The Juvenile Onset HD Resource Directory

Comprehensive Resource Guide for Families of Children Affected by Juvenile Onset HD

Information about federal, state and local programs

Huntington's Disease Society of America
The Juvenile Onset HD Resource Directory

Contributors: Stacey K. Barton, MSW, LCSW
HDSA Center of Excellence at Washington University
Anne Leserman, MSW, LISW
HDSA Center of Excellence at University of Iowa
Donna Ross, MSW, LICSW
HDSA Center of Excellence at the University of Washington
Lisa Snyder, MSW, LCSW
HDSA Center of Excellence at University of California, San Diego
Joanne Luz
HDSA Delaware Valley Chapter

And special thanks to our families and friends who also contributed to this publication

Published by the Huntington’s Disease Society of America with funding from the American Legion Child Welfare Foundation
Huntington's Disease (HD) is a hereditary brain disorder which leads to multiple physical and mental disabilities that increase over time. In people with the gene that causes HD, symptoms typically begin to appear between the ages of 35 and 45, but the disease may strike those as young as two or as old as 80. Juvenile onset Huntington's Disease (JHD) affects fewer than 10% of all individuals with HD.

JHD often presents different symptoms and challenges than adult onset HD. Ordinary issues of childhood and adolescence are intertwined with the progressive multiple disabilities caused by the disease.

There are programs at the Federal, State and community level which can help families meet the needs of their child or children with JHD. However, finding these programs and getting access to services can be challenging to even the most patient caregiver. Helping families facing JHD locate programs in their region is the goal of this guide.

The Juvenile Onset Huntington's Disease Resource Guide is the result of extensive research and collaboration with social workers, medical professionals and HD families across the country. Our goal is to present as complete a listing of useful resources as possible.

If you have a resource you would like to share, please email HDSA at Hdsainfo@hdsa.org so we can add it to the web based version of this directory.
# Table of Contents

**Supplemental Security Income**

- How does the Social Security Administration define “disabled”?.......................................................... 1
- What to expect when you apply .................................................................................................................. 1
- Statements from the child’s medical team.................................................................................................. 1

**TEFRA**

- Home Care for Children.............................................................................................................................. 3
- State Programs for Children with Special Healthcare Needs................................................................. 3
- A note on web addresses.............................................................................................................................. 3

**Federal/National Programs** .................................................................................................................. 5

- Federal Programs........................................................................................................................................ 5
- National Organizations............................................................................................................................... 5

**State and Community Resources**

- ALABAMA .................................................................................................................................................. 9
  - State Agencies.......................................................................................................................................... 9
  - Community Resources............................................................................................................................. 9
- ALASKA .................................................................................................................................................... 10
  - State Agencies.......................................................................................................................................... 10
  - Community Resources............................................................................................................................. 10
- ARIZONA ................................................................................................................................................... 11
  - State Agencies.......................................................................................................................................... 11
  - Community Resources............................................................................................................................. 11
- ARKANSAS ................................................................................................................................................. 12
  - State Agencies.......................................................................................................................................... 12
  - Community Resources............................................................................................................................. 12
- CALIFORNIA ............................................................................................................................................. 13
  - State Agencies.......................................................................................................................................... 13
  - Community Resources............................................................................................................................. 13
- COLORADO ............................................................................................................................................... 15
  - State Agencies.......................................................................................................................................... 15
  - Community Resources............................................................................................................................. 15
- CONNECTICUT ........................................................................................................................................ 16
  - State Agencies.......................................................................................................................................... 16
  - Community Resources............................................................................................................................. 16
- DELAWARE ............................................................................................................................................... 17
  - State Agencies.......................................................................................................................................... 17
  - Community Resources............................................................................................................................. 17
- DISTRICT OF COLUMBIA .......................................................................................................................... 18
  - State Agencies.......................................................................................................................................... 18
  - Community Resources............................................................................................................................. 18
- FLORIDA ................................................................................................................................................... 19
  - State Agencies.......................................................................................................................................... 19
  - Community Resources............................................................................................................................. 19
- GEORGIA ................................................................................................................................................... 20
  - State Agencies.......................................................................................................................................... 20
  - Community Resources............................................................................................................................. 20
- HAWAI'I ..................................................................................................................................................... 21
  - State Agencies.......................................................................................................................................... 21
  - Community Resources............................................................................................................................. 21
- IDAHO ....................................................................................................................................................... 22
  - State Agencies.......................................................................................................................................... 22
  - Community Resources............................................................................................................................. 22
<table>
<thead>
<tr>
<th>State</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>NEW YORK</td>
<td>47</td>
</tr>
<tr>
<td>NORTH CAROLINA</td>
<td>49</td>
</tr>
<tr>
<td>NORTH DAKOTA</td>
<td>51</td>
</tr>
<tr>
<td>OHIO</td>
<td>52</td>
</tr>
<tr>
<td>OKLAHOMA</td>
<td>53</td>
</tr>
<tr>
<td>OREGON</td>
<td>54</td>
</tr>
<tr>
<td>PENNSYLVANIA</td>
<td>55</td>
</tr>
<tr>
<td>PUERTO RICO</td>
<td>57</td>
</tr>
<tr>
<td>RHODE ISLAND</td>
<td>58</td>
</tr>
<tr>
<td>SOUTH CAROLINA</td>
<td>59</td>
</tr>
<tr>
<td>SOUTH DAKOTA</td>
<td>60</td>
</tr>
<tr>
<td>TENNESSEE</td>
<td>61</td>
</tr>
<tr>
<td>TEXAS</td>
<td>62</td>
</tr>
<tr>
<td>UTAH</td>
<td>64</td>
</tr>
<tr>
<td>VERMONT</td>
<td>65</td>
</tr>
<tr>
<td>VIRGINIA</td>
<td>66</td>
</tr>
<tr>
<td>WASHINGTON</td>
<td>67</td>
</tr>
<tr>
<td>WEST VIRGINIA</td>
<td>68</td>
</tr>
<tr>
<td>WISCONSIN</td>
<td>69</td>
</tr>
</tbody>
</table>
Supplemental Security Income

Supplemental Security Income (SSI) is a federal program of cash assistance to disabled needy individuals of any age, including children. Under SSI, children are considered disabled if they have a physical or mental condition which is so severe that it results in marked and severe functional limitation. The individual’s condition must last or be expected to last at least twelve (12) months, or be expected to result in the child’s death.

Everyone eligible for Social Security Disability Insurance (SSDI) benefits is also eligible for Medicare after a 24-month qualifying period. The first 24 months of disability benefit entitlement is the waiting period for Medicare coverage. Some states provide an additional cash benefit to individuals receiving SSI.

The exact amount of SSI for which a claimant is entitled depends on what the individual (or the parents in the case of a child) owns and how much income he or she has. Eligibility requirements and benefit payments for federal SSI benefits are identical throughout the 50 states and the District of Columbia. A disability law attorney can also provide state-specific information and guidance in planning for eligibility for SSI benefits.

The HDSA Chapter Social Workers and the Center of Excellence Social Workers are very knowledgeable about the resources in their state and region. Social workers will help you get started with services, and then help with advocacy as needed.

How does the Social Security Administration define “disabled”?

An individual under age 18 is “disabled” if he or she has a medically determinable physical or mental impairment, which:

- results in marked and severe functional limitations; and
- can be expected to result in death; or
- has lasted or can be expected to last for a continuous period of not less than 12 months.

If the individual is age 18 or older, the disability must also result in the inability to do any substantial gainful activity before benefits are granted.

What to expect when you apply

When you file an application for SSI benefits based on disability, the agency must first decide whether your family meets the income and resource criteria and other eligibility requirements.

They will ask for:

- Information about your child’s physical or mental impairment(s);
- names, addresses, and telephone numbers of doctors, hospitals and any other medical sources he/she has seen;
- Dates of treatment and the kinds of treatment the child has received from doctors, hospitals and other medical sources;
- Names of each prescription and non–prescription medicine that he/she takes and the doctor who prescribed it;
- The kinds of medical tests that have been performed, when and where they were done, and the name of the prescribing physician;
- The name, address, and telephone number of the child’s school and teacher.

They will contact doctors, hospitals, schools, teachers, therapists, relatives or others who can provide useful information about your child’s impairment(s) and functioning.

If they cannot get enough information from your doctors and other people to decide if your child is disabled, they may arrange and pay for an examination or testing by a qualified medical professional (who may be your own physician, psychologist, optometrist, or speech/language pathologist or other healthcare provider).

Statements from the child’s medical team

In the application for SSI benefits, you will include statements from the child’s medical team for the DDS examiners. If possible, have the child examined by an HD specialist, who may be able to make a stronger case based on their expertise. You can find an HD specialist in your area by contacting an HDSA Center of Excellence or your local HDSA Chapter.
The medical team's written statement should include the fact that the child has symptomatic JHD, not just a genetic condition. The statements should be as specific as possible, including the child's diagnosis, a description of the child's disabilities and their prognosis. This is especially important because JHD is a rare disorder and the physicians and examiners at Disability Determination Services (DDS) may not understand its impact on the child.

As you go through the application and appeals process, remain courteous to the people you deal with at Social Security and at the DDS office. They will probably do more for you if you have a friendly relationship. Keep copies of all the child's medical records. Respond promptly to letters and notices and go to any medical exams scheduled by DDS. Do not let important deadlines lapse. If you have questions, calling your local DDS office may be easier and more effective than trying to get through to the Social Security office.

**Medicaid**

Medicaid is a jointly funded and administered state and federal welfare program that pays the qualifying medical expenses for those individuals whose financial resources fall below the program's established minimums. Medicaid may pay for such services as hospital and doctor bills not covered by insurance, home healthcare services, medical transportation, and nursing home care.

Medicaid is administered by each state, unlike Medicare, and both are partially funded by the U.S. Centers for Medicare & Medicaid Services (CMS). No two states' Medicaid programs are alike, yet there are certain federally mandated standards common to all Medicaid programs across the nation.

In most states, once a child gets SSI benefits, they can also enroll in Medicaid to help pay medical bills. Many states also have waiver programs under which an individual who is disabled but does not meet the financial criteria may still become eligible for benefits. Eligibility for Medicaid, including home and community-based services waivers, is not determined by the Federal government.

**Medicaid at a Glance**


Most recent overview of the Medicaid Program. This 12 page pdf includes:

- Key Eligibility Groups
- Mandatory State Plan Services
- State Chart
- Federal Poverty Guidelines
**Home Care for Children**

In some states, children under age 18 who need institutional-level care and live at home may keep Medicaid eligibility while getting home care, if that care is less costly to the government than institutional care. This program is called TEFRA and is also known as the Katie Beckett option. To qualify for TEFRA benefits, the child must be disabled according to the Supplemental Security Income (SSI) definition of disability and must meet the medical-necessity requirement for institutional care. Because there are so few nursing home beds available for children under the age of 16, TEFRA may be an important option for late stage care.

TEFRA is different than Medicaid in that parental income and resources are not considered in awarding benefits. Only the income and resources of the child are counted. Parents may be required to pay a parental fee calculated by using the parents adjusted gross income (before taxes) from last year’s tax return and comparing it with the Federal Poverty Guideline.

Children who receive SSI but lose coverage intermittently due to fluctuating parental income may be eligible for TEFRA benefits in the months they do not receive SSI. The child’s parent or guardian can apply for TEFRA at the Medicaid office in the child’s county of residence.

**State Programs for Children with Special Healthcare Needs**

Most states have programs for Children with Special Healthcare Needs. Many of these programs are listed in the Resources by State section of this guide. Among these programs is the Katie Beckett Waiver, also known as the Deeming Waiver of the 2176 Model Waiver. The waiver is part of the Medicaid program and it pays for home-based medical services for children with chronic disabilities whose parents make too much to meet the income requirements of Medicaid. The program is administered by individual states and provisions vary. Ask your primary care physician or medical social worker about additional programs in your state.

**A note on web addresses**

Every attempt has been made to provide you with the best possible links to information in this Resource Guide, but website addresses can and do change. If you click on a link or enter a web address and it does not work, don’t give up. You can use a search engine, like Google, Yahoo or Ask.com, to find the website. All you need to do is copy the name of the agency or organization (not the old web address) into the search box and you will most likely be taken to the new web address of that organization.
Federal/National Programs

**Federal Programs**

**Government Benefits**
www.govbenefits.gov

GovBenefits.gov is the official benefits website of the U.S. government with information on over 1,000 benefit and assistance programs.

**Disability Information**
www.disabilityinfo.gov

Online connection to the federal government’s disability-related information and resources, including links on applying for SSI and on state Children’s Health Insurance Programs (CHIP).

**US Department of Health and Human Services – Administration for Children and Families**
Administration on Developmental Disabilities (ADD)
www.acf.hhs.gov/programs/add

Link to federally funded State Councils on Developmental Disabilities (SCDD) which ensure that individuals with developmental disabilities and their families have access to culturally competent services, supports, and other assistance.

**Centers for Medicare and Medicaid Services (CMS)**
www.cms.hhs.gov/home/medicaid.asp

CMS administers the Medicare, Medicaid and the State Children’s Health Insurance programs (SCHIP)

**Benefit Eligibility Screening Tool (BEST)**
http://connections.govbenefits.gov/ssa_en.portal

Based on your answers to questions, this tool will list Social Security benefits for which your and/or your child might be eligible and provides information about how to qualify and apply.

**Center for Mental Health Services (CMHS)**
www.mentalhealth.samhsa.gov/cmhs

Meeting the mental health needs of children and their families through community-based systems of care. Website provides a state by state services locator.

**Department of Education (DOE) – Office of Special Education and Rehabilitative Services (OSERS)**
www.ed.gov/about/offices/list/osers/index.html

OSERS website includes a wide array of information for families, school districts and states in three main areas: special education, vocational rehabilitation and research.

**Insure Kids Now**
www.insurekidsnow.gov

A Children’s Health Insurance Program that works to provide free and low-cost health insurance to children under 19. 877-KIDS-NOW connects you to your State program.

**Social Security Online**
www.socialsecurity.gov/disabilityresearch/wi/medicare.htm

Medicare Information

**Ticket to Work**
www.ssa.gov/work/receivingbenefits.html

Vocational rehabilitation, training, job referrals, and other ongoing support and services for persons over 18 receiving SSI. Request assistance in job training, locating employers, information about work incentives, etc.
National Organizations

The ARC
www.thearc.org

The ARC is the world’s largest community-based organization of and for people with intellectual and developmental disabilities. It provides an array of services and support for families and individuals and includes over 140,000 members affiliated through more than 780 state and local chapters across the nation.

Short Term Assistance and Referral (STAR)
http://www.arc-anchorage.org/star.htm
    ph 907.777.0113

In many states, ARC offers the STAR Project which provides short term assistance to families of children or adults who experience developmental disabilities.

Some of the ways the STAR Project can help:

- Provide information about programs and/or people who can help
- Help arrange meetings to get services started
- Help with the application process for services through the Division of Senior and Disabilities Services (DSDS), respite programs, SSI, Medicaid, and other assistance programs
- Assist in locating adaptive equipment
- Assist in locating natural supports
- Provide short term respite care if the family is not enrolled in a respite program
- Attend educational and medical meetings when requested by the family
- Assist with behavioral issues
- Listen, problem solve, and plan for the future.

American Speech-Language-Hearing Association
www.asha.org/public

Directory of Speech-Language Pathologist and Audiologists

The Center for Children with Special Needs
www.cshcn.org

Thoughtful resource for parents of children with chronic health problems in various areas including creating care organizers, finding dental care, child care and the ADA, etc.

Centers for School Mental Health – Technical Assistance Centers
www.smhp.psych.ucla.edu
www.csmha.umaryland.edu

These national training and technical assistance centers focused on mental health in schools were established with partial support from the U.S. Department of Health and Human Services and the Center for Mental Health Services. One center is at UCLA and the other is at the University of Maryland at Baltimore. The web sites include information and resources on school-based mental health programs.

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)
www.chadd.org

Tips and resources for parents of children with AD/HD.

Easter Seals
www.easterseals.com

Services, education, outreach, and advocacy for people with disabilities. Nationwide Directory for the Easter Seals Child Development Center, offering top-quality inclusive care at centers across the country.

Family Voices
www.familyvoices.org

Organization that advocates for family-centered care for all children and youth with special healthcare needs and/or disabilities. Links to individual state organizations.

IDEA Partnership
www.ideapartnership.org

The IDEA Partnership is dedicated to improving outcomes for students and youth with disabilities by joining state agencies and stakeholders through shared work and learning. The web site includes many helpful resources for schools, families and advocates.
Intervention Central  
www.interventioncentral.org  
Resources and tools to promote positive classroom behaviors and foster effective learning.

The Kaiser Family Foundation  
www.kff.org/medicaid/index.cfm  
Data and information on the Medicaid and CHIP programs by state.

National Alliance on Mental Illness  
www.nami.org  
The NAMI organization operates at the local, state and national levels. Each level of the organization provides support, education, information and referral and advocacy in the area of mental illness. Local programs offer:

- Up-to-date information about medications, side effects, and strategies for medication adherence
- Workshops for problem solving, listening, and communication techniques
- Strategies for handling crises and relapse
- Care for the caregiver: coping with worry, stress, and emotional overload

National Assistive Technology Technical Assistance Partnership (ANATTAP)  
www.resnaprojects.org/nattap/at/statecontacts.html  
Helping individuals remain independent with assistive technology. Links to individual state’s assistive technology programs – equipment loans, training, financing, etc.

National Information Center for Children and Youth with Disabilities (NICHCY)  
www.nichcy.org  
NICHCY is an information and referral center that provides information on disabilities and disability-related issues (including mental illnesses) for families, educators, and other professionals, with a special focus on children and youth – birth to age 22.

Pacer Center  
www.pacer.org  
Minnesota-based PACER Center (Parent Advocacy Coalition for Educational Rights) offers excellent publications on schooling and navigating healthcare.

ParentsMedGuide.org  
www.parentsmedguide.org  
Guide for medications used in treating children and youth with depression or ADHD.

SchoolMentalHealth.org  
www.schoolmentalhealth.org  
This site offers school mental health resources not only for clinicians, but also for educators, administrators, parents/caregivers, families, and students. The resources included in the site emphasize practical information and skills based on current research, including prominent evidence based practices, as well as lessons learned from local, state, and national initiatives.

School Psychiatry Program and the Mood & Anxiety Disorders Institute (MADI) Resource Center  
www.schoolpsychiatry.org  
The School Psychiatry Program and the Mood & Anxiety Disorders Institute (MADI) Resource Center, both part of the Department of Psychiatry at Massachusetts General Hospital (MGH), jointly created Schoolpsychiatry.org. This website is committed to enhancing the education and mental health of every student in every school. The website has resources for parents, educators and clinicians to ensure that each group is working together to support children and teens with mental health conditions.

Specialized Training of Military Parents (STOMP)  
www.stompproject.org  
The only National Parent Training and Information Center for military families with special needs children. Offers assistance with issues such as: maintaining continuity of special education programs, finding specialists who take TRICARE, and identifying available state services.
Technical Assistance Alliance for Parent Centers  
www.taalliance.org
The Technical Assistance Alliance for Parent Centers is an innovative project that supports a unified technical assistance system for the purpose of developing, assisting and coordinating Parent Training and Information Projects and Community Parent Resource Centers under the Individuals with Disabilities Education Act (IDEA).

Wrightslaw: Special Education Law  
www.wrightslaw.com
Website designed for families, advocates, educators, and attorneys looking for accurate, up-to-date information about special education law and advocacy for children with disabilities.
State and Community Resources

ALABAMA

State Agencies

Alabama Medicaid Agency
www.medicaid.state.al.us
Eligibility and qualifying information, applications and forms.

Alabama Department of Education – Special Education
www.alsde.edu/html/sections/section_detail.asp?section=65&footer=sections
Documents, forms and checklists about Alabama's special education programs.

Alabama Department of Public Health SCHIP
www.adph.org/allkids
Alabama's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Alabama Department of Rehabilitation Services – Children’s Rehabilitation Services
www.rehab.alabama.gov/crs
Program information on specialty clinical and therapeutic services, care coordination, assistive technology and other services provided to persons with disabilities through 15 community-based offices. Children with neurological conditions are eligible for these services.

Alabama Department of Rehabilitation Services – Teen Transition Clinic
www.rehab.state.al.us/Home/default.aspx?url=/Home/Services/CRS/ProgramsYouth+Connection/Teen+Transition+Clinic
Transitional services for youth with special healthcare needs from ages 12-21. A partnership of CRS, Vocational Rehabilitation Service (VRS), State of Alabama Independent Living Service (SAIL) and other community providers.

Community Resources

Alabama Disabilities Advocacy Program (ADAP) – The University of Alabama
www.adap.net
Information and referral services and parent trainings on special education topics. Children’s Advocacy Team (CHAT) represents individuals in certain cases involving denial of disability services.

Alabama Lifespan Respite Resource Network
http://alabamarespite.org
Provides respite-related information to families in Alabama, connects families with respite care payment resources, coordinates respite and caregiving trainings, and maintains databases of respite care providers and possible funding resources.

Alabama Parent Training & Info Network for Children with Disabilities
www.alabamaparentcenter.com/ALPTI
Information and training for families of children with disabilities to effectively access community and other resources, and understand special education law and dispute resolution.
**ALASKA**

*State Agencies*

Alaska Public Assistance – Medicaid  
www.hss.state.ak.us/dpa/programs/medicaid  
Eligibility and qualifying information, applications and forms.

Alaska Department of Education & Early Development – Special Education  
www.eed.state.ak.us/tls/sped/Resources.html  
Special Education Handbook, Resources for Parents and Educators and information on understanding the eligibility for Intensive Needs Special Education, among other resources.

Denali Kid Care  
www.hss.state.ak.us/dhcs/DenaliKidCare  
Alaska’s Children’s Health Insurance program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Alaska Health and Social Services – Senior & Disabilities Services – Developmental Disabilities Program  
www.hss.state.ak.us/dsds/dd/default.htm  
Information on Alaska’s programs for children with disabilities, including Special Education, Home and Community-based Waiver Services for Children with Complex Medical Conditions, and Developmental Disabilities eligibility.

Alaska Department of Education & Early Development – Mediation, Complaints & Due Process  
www.eed.state.ak.us/tls/sped/Mediation.html#aksystem  
State mediation system for disputes between parents and a district that they are unable to resolve.

Alaska Health and Human Services – Office of Children’s Services – Residential Care  
www.hss.state.ak.us/ocs/ResidentialCare/default.htm  
Mental Health Residential Care for Children & Youth. Short-term emergency shelter and long-term residential treatment.

*Community Resources*

Stone Soup Group  
www.stonesoupgroup.org  
Parent Training and Information Project that offers assistance in obtaining services, liaison assistance between clinics, the family and the child’s medical home, referrals to community and other services.
ARIZONA

State Agencies

Arizona Healthcare Cost Containment System – Medicaid
www.azahcccs.gov
Eligibility and qualifying information, applications and forms.

Arizona Department of Education – Exceptional Student Services
http://www.ade.az.gov/ess/specialprojects/pinspals
Parent Information Network of specialists who provide on-site and phone consultation, training, resources, and information and referrals to support parents of special education students. Links to booklets and other information.

Kids Care
www.kidscare.state.az.us
Arizona’s Children’s Health Insurance Program (CHIP) which offers affordable healthcare for children and teens not eligible for Medicaid.

Arizona Department of Economic Security – Division of Developmental Disabilities
Information and eligibility requirements for services to persons with disabilities.

Arizona Department of Health Services – Public Health Prevention Services – Office for Children with Special Care Needs
http://www.azdhs.gov/phs/ocshcn
Gateway to Children’s Rehabilitative Services, Medical Home Coordinated Healthcare Services, Parent to Parent Support, Advocacy and Protection and other state agencies and programs for children with disabilities.

First Call for Help – Community Information and Referral
http://www.cir.org
Database of local resources from nonprofit and government agencies in Arizona.

Community Resources

Raising Special Kids
http://www.raising.special.kids.org/services/programs.aspx
Parent Training and Information Network providing training, resources, and support to families of children with disabilities and special healthcare needs in Arizona. Parent to parent support and assistance with special education issues and transition services.

Pilot Parents of Southern Arizona
www.pilotparents.org
Parent Training and Information Center serving Cochise, Gila, Graham, Greenlee, La Paz, Pima, Pinal, Santa Cruz and Yuma counties. Provides resources, training and support to families of children with disabilities. Parent to Parent assistance with the special education process, etc.
ARKANSAS

State Agencies

Arkansas Medicaid
www.medicaid.state.ar.us
Eligibility and qualifying information, applications and forms.

Arkansas Department of Education – Special Education – Direct Services Support
arksped.k12.ar.us/sections/dss.html
Information on Arkansas’ special education programs. Links to key resources.

AR Kids First
www.arkidsfirst.com/home.htm
Arkansas’ Children’s Health Insurance Program (CHIP) which offers affordable healthcare for children and teens not eligible for Medicaid.

Arkansas Department of Human Services
www.arkansas.gov/dhs/homepage.html
Service directory of Medicaid and mental health services, services for persons with developmental disabilities, respite care services, and more.

Arkansas Department of Human Services – Division of Developmental Disabilities Services
www.arkansas.gov/dhs/ddd/NewWebsite
Information on Arkansas’ community-based services, waiver services, application directions and guides to Services for Children with Disabilities.

Arkansas Department of Human Services – Division of Behavioral Health Services
www.arkansas.gov/dhs/dmhs
Community-based mental health services provided statewide through 15 private, non-profit community mental health centers (CMHCs), their affiliates, and three mental health clinics.

Disability Rights Center – Client Assistance Program
www.arkdisabilityrights.org/cap.html
Information, education and referrals to assist disabled persons receiving or seeking services. Individual advocacy is available in special instances.

Community Resources

Arkansas Disability Coalition
http://www.adcpti.org
Parent Training and Information Center that teaches parents of children ages 0-26, with special education needs, how to develop and monitor effective educational plans for their children.

Arkansas Support Network
www.supports.org
Parent Training and Information Center that assists parents in obtaining community living services, supported living, personal care, supported employment and other services for their children with disabilities.

FOCUS, Inc.
www.focusinconline.org
Parent Training and Information Center that assists parents in advocating for their children with disabilities in the special education process and provides Medicaid Waiver services such as case management and direct care.
**CALIFORNIA**

**State Agencies**

California Department of Healthcare Services – Medi-Cal  
www.medi-cal.ca.gov  
Eligibility and qualifying information, applications and forms.

California Department of Education/Special Education – Family Involvement and Partnerships  
www.cde.ca.gov/sp/se/fp  
Information, resources and support for parents, guardians and families of children with disabilities.

California Healthy Families Program  
www.healthyfamilies.ca.gov  
California’s Children’s Health Insurance Program (CHIP) which offers affordable insurance for children and teens not eligible for Medicaid.

Department of Disability Services  
www.dds.ca.gov/EarlyStart/Home.cfm  
Healthcare providers, early intervention specialists, therapists, and parent resource specialists for young children with disabilities.

California Department of Healthcare Services  
California Children’s Services (CCS)  
www.dhcs.ca.gov/services/ccs/Pages/default.aspx  
Gateway to the state program for children, up to age 21, with special healthcare needs, including children with diseases of the nervous system.

California Department of Mental Health – Programs for Children and Youth  
www.dmh.ca.gov/default.asp  
Services for children and youth directly provided at the local level by counties and their contract providers. Directory of county mental health agencies. Eligibility, applications and links to county offices.

**Community Resources**

Chinese Parents Association for the Disabled  
www.cpad.org  
In Anaheim, providing support and assistance with special education issues.

Fiesta Educativa  
www.fiestaeducativa.org  
Community Parent Resource Centers (CPRC) for parents of children with disabilities in the Latino and Chinese communities with links to Regional Committees.

Matrix Parent Network and Resources Center  
www.matrixparents.org  
Based in Marin, Napa, Solano and Sonoma counties, Matrix is a parent-run information and resource center providing no-cost information, education and emotional support services to families of children with special needs (birth through age 26).

Parents Helping Parents  
www.php.com/specialed  
PHP provides a wide range of services to help parents better understand, support and advocate for their children in special education programs.

Rowell Family Empowerment of Northern California, Inc.  
www.rfenc.org/respite.php  
In Shasta, Butte and Tehama counties, PFENC offers no-charge respite services to families who have a child, ages 0-18 with a disability, who is a client of Far Northern Regional Center.
Support for Families of Children with Disabilities
www.supportforfamilies.org/family_links.html
In San Francisco, SFCD assists families in accessing the mental health system.

Team of Advocates for Special Kids (TASK)
www.taskca.org
In Anaheim, Long Beach and San Diego, TASK is a federally-funded Parent Training and Information Center, serving children 0-26. Special Education advocates offer one-to-one assistance over the telephone and answer questions for parents and professionals concerning their child's or client's rights.

Vietnamese Parents with Disabled Children Association, Inc. (VPDCA)
www.vpdca.org
Providing support and assistance with special education issues in Carson, CA.
COLORADO

State Agencies

Colorado Dept. of Healthcare Policy and Financing – Medicaid
www.colorado.gov/cs/Satellite/HCPF/HCPF/1197364086675
Medicaid and Child Health Plan Plus programs as well as a variety of other programs for Colorado’s low-income families, the elderly and persons with disabilities.

Colorado Department of Education – Exceptional Student Leadership Unit (CDE – ESLU)
www.cde.state.co.us/index_special.htm
Resources on Colorado’s Special Education programs and information on educational specialists, parent-professional partnerships and more.

Colorado Child Health Plan Plus
www.cchp.org
Colorado’s Children’s Health Insurance Program (CHIP) which offers affordable healthcare for children and teens not eligible for Medicaid.

Colorado Department of Human Services
www.cdhs.state.co.us
Directory of Colorado’s 64 county departments for social/human services, public mental health system, and services for people with developmental disabilities.

Colorado Department of Human Services – Division for Developmental Disabilities (DDD) and Community Centered Boards (CCBs)
www.cdhs.state.co.us/ddd
Information hub for Colorado’s developmental disability services. Eligibility, information for individuals and families, FAQs, and links to the individual Community Centered Boards which administer services.

Colorado Department of Human Services – Disability Determination Services (DDS)
www.cdhs.state.co.us/dds
Eligibility rules and procedures of the state agency that makes disability determinations for Social Security.

Colorado Department of Public Health and Environment – Children with Special Healthcare Needs Unit
www.cdphe.state.co.us/ps/hcp/home/respite.html
Program for children and teens with Special Healthcare Needs that can evaluate your family’s needs, talk to you about medical care, services, insurance and more. A source for short term respite care.

Community Resources

Assistive Technology Partners
uchsc.edu/atp
Assistance through the University of Colorado Denver with obtaining assistive technology: wheelchairs, communication devices, computers, electronic aids to daily living, and learning/cognitive aids.

CCA: Colorado Citizens for Accountability
www.coloradocitizensforaccountability.org
- Information on guardianship and durable power of attorney
- Advocacy training for those who have family members in the hospital
- Support for families/individuals dealing with legal issues in the medical system

PEAK: Colorado’s Parent Training and Information Center
www.peakparent.org
PEAK Parent Center, the Colorado Department of Education, and the Colorado Developmental Disabilities Council provide person-centered special educational planning assistance to people with disabilities between the ages 3-30 years old. Low or no-cost services.
CONNECTICUT

State Agencies

Connecticut Department of Social Services – Medicaid
www.ct.gov/dss/cwp/view.asp?a=2353&q=305218#MAID
Information hub for Connecticut’s healthcare programs, including Medicaid. Link to Medicaid brochure.

Connecticut State Department of Education: Special Education
Links to special education resources, including IEP forms and useful links outside the agency.

Connecticut Husky Healthcare for Uninsured Children and Youth
www.huskyhealth.com
Connecticut’s Children’s Health Insurance Program (CHIP) which offers affordable healthcare for children and teens not eligible for Medicaid.

Connecticut Department of Developmental Services (DDS)
www.ct.gov/dds
Eligibility and application information for services to persons with developmental disabilities, including case management, family support services, respite, etc.

Connecticut Medical Home Initiative for Children & Youth with Special Healthcare Needs (CYSHCN)
www.ct.gov/dph/cwp/view.asp?a=3138&q=387702
Information on Connecticut’s Medical Home program for children with disabilities, in which a pediatric healthcare professional works in partnership with the family to access and coordinate special care, educational services, out-of-home care, family support, respite and other public and private community services.

Connecticut Department of Social Services – ConnPACE
www.connpace.com
Links to multiple programs that provide assistance with prescription costs to individuals with disabilities.

Connecticut Department of Mental Health and Addiction Services
www.ct.gov/dmhas
Service locator and links to 24-hr crisis services.

Community Resources

Connecticut Parent Advocacy Center (CPAC)
www.cpacinc.org
Parent advocates offering information and support to families of children with any disability or chronic illness, age birth through 26.

Disabilities Network of Eastern Connecticut
www.dnec.org
Advocacy services for individuals with disabilities who are having difficulty obtaining benefits, social services, access to public facilities, or when discrimination is taking place in employment, education, or communication.
DELAWARE

State Agencies

Delaware Health and Social Services – Medicaid
www.dhss.delaware.gov/dss/medicaid.html
Eligibility and qualifying information, applications and forms.

Delaware Department of Education: Special Education
http://www.doe.state.de.us/programs/specialed
Links to special education services.

Delaware Healthy Children Program
www.state.de.us/dhss/dss
Delaware's Children's Health Insurance Program (CHIP) which offers affordable healthcare for children and teens not eligible for Medicaid.

Delaware Health and Social Services – Division of Developmental Disabilities Services
www.state.de.us/dhss/dds/index.html
Information on applying for services, including family support, case management, medical services, respite, etc.

Delaware Division of Child Mental Health Services
http://kids.delaware.gov/cmhs/cmhs.shtml
Accessible, effective behavioral health treatment services for children in collaboration with families and service partners.

Community Resources

Delaware Assistive Technology Initiative
www.dati.org
Program to make assistive technology available at no or low cost, including equipment recycling.

Parent Information Center of Delaware (PIC)
www.picofdel.org
Parent Information and Training Center providing support and information to parents of children with disabilities. Parent to parent consulting on special education topics, seminars and training, and online resource center.
DISTRICT OF COLUMBIA

State Agencies

District of Columbia Department of Health – Medicaid and DC Healthy Families Insurance Program
www.dhcf.dc.gov
Links to Medicaid and DC Healthy Families Insurance programs (SCHIP) which offers affordable healthcare for children and teens not eligible for Medicaid.

District of Columbia Public Schools – Office of Special Education
www.k12.dc.us/offices/ose/index.htm
Information on the District’s special education programs and policies.

District of Columbia Department on Disability Services
www.dds.dc.gov/dds/site/default.asp
Website under construction. Promises information regarding applying for services, how to find qualified providers and other key resources.

District of Columbia Health Services for Children with Special Needs, Inc.
www.hscsn-net.org
Innovative care management network coordinating health, social, and education services for the pediatric Supplemental Security Income (SSI) and SSI-eligible populations of Washington, DC.

District of Columbia Department of Mental Health – Access Helpline
www.dmh.dc.gov/dmh/cwp/view,A,3,Q,515987,dmhNav,[31250].asp
Overview of the DC Mental Health Access Helpline (1-888-793-4357), which is a 24-hour a day telephone service for emergency or ongoing mental healthcare services for children, youth and adults.

Community Resources

Advocates for Justice and Education, Inc.
www.AJE-DC.org
Parent Training and Information Center that offers Parent to Parent support network. Provides professional individual representation in situations when the intervention of a third party is necessary to ensure that appropriate services are being made available to children with disabilities.

HSC (Health Services for Children) Pediatric Center
www.hscpediatriccenter.org
Hospital assisting children to adapt to lifelong issues related to chronic illness or their disabilities. Provides a link to HSC Foundation’s Community Services Resource Directory of healthcare and social services providers, government agencies, nonprofit organizations, and advocates for community services throughout the District of Columbia.
State Agencies

Florida Department of Children and Families – Medicaid  
www.dcf.state.fl.us/ess  
Access to Florida’s system of information about benefits and eligibility for Medicaid and other public assistance programs.

Florida Department of Education – Exceptional Education and Student Services  
www.fldoe.org/ese/ese-home.asp  
Basic information on state programs and the responsibilities of school districts.

Healthy Kids  
www.healthykids.org  
Florida’s Children’s Health Insurance Program (CHIP) which offers affordable healthcare for children and teens not eligible for Medicaid. Includes dental benefits.

State of Florida – Agency for Persons with Disabilities  
www.apd.myflorida.com/customers  
Information on new 4-tier waiver program for person with disabilities. Links to brochures and applications.

Florida Department of Health – Children’s Medical Services (CMS)  
http://www.cms-kids.com  
Medical, therapeutic and supportive services to children with special healthcare needs who are eligible for Medicaid, KidCare or CMS Network Safety Net. Eligibility rules, benefits and other information.

Florida Department of Children and Families – Mental Health  
www.dcf.state.fl.us/mentalhealth  
Mental healthcare resources for children and adults. Links to the 15 district offices.

Community Resources

Central Florida Parent Center, Inc.  
www.cflparents.org  
Parent Training and Information Center that assists parents of children with disabilities and young adults with disabilities to cooperatively and effectively participate in planning and decision-making related to early intervention, educational, and transitional services under IDEA.

Florida Alliance for Assistive Service and Technology  
http://faast.org  
Statewide loan program for assistive technology devices which allows individuals to try out and train on devices. Includes classified ads to buy, sell or trade assistive technology. Includes eligibility requirements.

Family Network on Disabilities of Florida  
www.fndfl.org/Programs.asp  
Links to local programs throughout the state. Parent Training and Information Centers, transition services and parent to parent support.
GEORGIA

State Agencies

Georgia Department of Human Services, Division of Family and Children Services – Medicaid
http://dfcs.dhr.georgia.gov/portal/site/DHR-DFCS
State Medicaid program, accessed through Services menu, with application information and list of county offices.

Georgia Department of Education – Division for Exceptional Students
www.gadoe.org/ci_exceptional.aspx
Services and support information on Georgia’s special education programs.

PeachCare for Kids
www.peachcare.org
Georgia’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Georgia Department of Community Health – Children’s Medical Services.
www.health.state.ga.us/programs/specialneeds/index.asp
Coordinated system of medical/healthcare for eligible children, birth to 21, with chronic medical conditions, provided through a network of 21 district offices at low or no cost, depending on eligibility.

Georgia Department of Behavioral Health and Developmental Disabilities
www.dbhdd.georgia.gov/portal/site/DBHDD
Links to Developmental Disabilities programs and services, regional office locator and information on waiver programs.

Georgia Department of Human Resources – Behavioral Health Link
www.mygcal.com
24-hour Crisis and Access Line, plus Resource Base with local resources for children and adults with mental health and developmental disabilities.

Georgia Department of Labor – Vocational Rehabilitation Program – Disability Adjudication Services
www.vocrehabga.org/dasfacts.html
Information on the program that determines disability for the purpose of SSI eligibility.

Community Resources

Fragile Kids Foundation
www.fragilekids.org
Foundation that provides loans and grants of equipment for Georgia’s medically fragile children. Equipment may include a wheelchair lift installed in a family’s van, toileting systems, lifting systems, bath chairs and specialized car seats.

Georgia Advocacy Office, Inc.
http://www.thegao.org
Private not-for-profit corporation that offers assistance to persons with disabilities to obtain special education services; also delivers parent training programs and locates funding for assistive technology.

Georgia Assistive Technology Act Program – Tools for Life
www.gatfl.org
Demonstrations, trainings and help with obtaining assistive technology. Extensive links to internet resources.

Georgia Children’s Network (GCN)
http://groups.yahoo.com/group/GA-ChildrensNetwork
Online discussion group in GA bringing parents and grandparents of special needs children together with other parents, advocates, professionals, service providers and community organizations

Parent to Parent of Georgia, Inc.
www.parenttoparentofga.org
Support and information for parents of children with disabilities. Parent to parent support available. “Roadmap to Services” contains hundreds of web pages with a wealth of information on many topics of interest to families.
HAWAI‘I

State Agencies

Hawai‘i Department of Human Services – QUEST Hawai‘i
www.med-quest.us
Eligibility and qualifying information for Med-QUEST, which includes Medicaid and the Hawaii’s children’s health insurance program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Hawai‘i Department of Education – Special Education
www.doe.k12.hi.us/specialeducation/index.htm
Overview information on Hawaii’s special education programs, student’s rights, mediation procedures, etc.

Hawai‘i Department of Health – Developmental Disabilities Division
www.cmisb.org/default.asp
Application and eligibility information on home and community-based services, including family support services, chore and personal assistance, skilled nursing, respite care, etc.

Hawai‘i Department of Health – Children with Special Health Needs Branch
Care coordination, nursing and social work for low-income children ages 0-21 with disabilities. Some limited financial help with medical services.

Hawai‘i Department of Health – Children and Adolescent Mental Health Division (CAMHD)
www.hawaii.gov/health
Mental health services for children and youth accessed through Family Guidance Centers. Both school-based services and more intensive mental health services available.

Community Resources

Assistive Technology Resource Centers of Hawai‘i (ATRC)
www.atrc.org
ATRC utilizes demonstrations, outreach, technical assistance, public awareness, device loans and trials, financial lending and other programs to help match individuals with disabilities to assistive technologies. Offers a classified ad system for buying, selling and trading assistive technology devices.

Learning Disabilities Association of Hawai‘i
www.ldahawaii.org
Educational advocacy, training, support and other programs for children with disabilities. Offers PIN grants for speech-language pathology.

Special Parent Information Network (SPIN)
www.spinhawaii.org
Parent Training and Information Center that provides information, support and referral to parents of children and young adults with disabilities, including special education advocacy, community resources, etc.
IDAHO

State Agencies

Department of Health and Welfare – Medical Services
www.healthandwelfare.idaho.gov/Medical/tabid/61/Default.aspx
Medicaid and Children’s Health Insurance Program eligibility and qualifying information, applications and forms.

Idaho Department of Education – Special Education
www.sde.idaho.gov/site/special_edu
Information on Idaho’s special education programs, with links to the special education manual, Medicaid consent forms for school based services and dispute resolution.

Idaho Department of Health and Welfare – Idaho Health Plan Coverage
http://www.healthandwelfare.idaho.gov/?TabId=219
Idaho’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Idaho Department of Health and Welfare – Developmental Disabilities
healthandwelfare.idaho.gov/Medical/DevelopmentalDisabilities/tabid/120/Default.aspx
Information on Idaho’s programs for person with developmental disabilities, including family support programs, and service coordination.

Idaho Department of Health and Welfare – Children’s Services
Links to Medicaid, Children’s Special Health Needs and Children’s Mental Health services, FAQs, and links to regional offices.

Idaho Department of Health and Welfare – Children’s Special Health Program
www.cshp.dhw.idaho.gov
Consultation, information, technical assistance and referral services for the families of uninsured children who have chronic illnesses and disabilities.

Community Resources

Idaho Assistive Technology Project
www.idahoat.org
Assistance in obtaining assistive technology, a used equipment exchange, an alternative financing program, assistive technology support for schools, and training events throughout Idaho.

Children’s Disabilities Information
www.childrensdisabilities.info
Articles and resources including links to special needs stores, animal therapy opportunities, parent groups, etc.

Idaho Help Family Support 360 Project
Statewide community resource directory from the University of Idaho, Center on Disabilities and Human Development.

Idaho Parents Unlimited, Inc. (IPUL)
www.ipulidaho.org
Information hub for families of children with disabilities dedicated to promoting family-centered care. Includes links to the Idaho Parent Training and Information Center (PTI), where Parent Education Coordinators offer expertise on navigating disability services, agencies, and programs; Family 2 Family information and resource program; and the VSA Arts of Idaho.
ILLINOIS

State Agencies

Illinois Department of Health and Family Services – Medicaid
www.hfs.illinois.gov/programs
Eligibility and qualifying information, applications and forms.

Illinois State Board of Education: Special Education Services
http://www.isbe.net/spec-ed
Links to programs, definitions, publications, trainings and forms.

Illinois Department of Healthcare and Family Services – Illinois All Kids
www.allkids.com
Illinois’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Illinois Department of Human Services
www.dhs.state.il.us
Information hub with links to Developmental Disability, Disability and Rehabilitation, Disability Determination, Vocational Rehabilitation, Mental Health and Home Services Programs, among others.

Department of Human Services – Disability Determination Services
http://www.dhs.state.il.us/page.aspx?item=29979
Agency responsible for determining eligibility for SSI.

Community Resources

University of Illinois at Chicago – Division of Specialized Care for Children (DSCC)
http://www.ahs.uic.edu/dhd
Information and referrals to community resources offering care coordination, home care, Children’s Habilitation Clinic, etc. through 13 regional offices throughout the state.

Equip for Equality, Inc.
http://www.equipforequality.org
Statewide, cross-disability, comprehensive advocacy organization providing self-advocacy assistance, legal services, and disability rights education.

Family Matters – Parent Training and Information Center
http://www.fmptic.org
Information and trainings for parents about special education services for school aged children. Assistance with transition issues for students who will be leaving the educational system.

Family Resource Center on Disabilities
http://www.frcd.org
Information and training on Special Education Rights and due process, serving the 8 counties around Chicago.

Family Support Network of Illinois
http://www.familysupportnetwork.org
Information about home-based support services that help disabled individuals live at home and how to apply for them.

Project CHOICES
www.projectchoices.org
Illinois State Board of Education initiative that partners with local school districts to provide access for all students through general education. Offers ideas and tools for greater inclusion in general education classes.
INDIANA

State Agencies

Indiana Family & Social Services Administration – Office of Medicaid Policy and Planning – Medicaid
www.in.gov/fssa/2408.htm
Information hub on Indiana’s Medicaid program, Medicaid waiver programs, and Children’s Health Insurance Program.

Indiana Department of Education – Special Education
www.doe.in.gov/exceptional/speced/welcome.html
Information hub for Indiana’s Special Education programs with links to rules, monitoring, due process, etc.

Indiana Family and Social Services Administration – Hoosier Healthwise – Children’s Health Insurance Program
www.healthcareforhoosiers.com
Indiana’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Indiana Family and Social Services Administration – Division of Disability and Rehabilitative Services
www.in.gov/fssa/2328.htm
Services for people with disabilities, provided through 8 regional offices that include caregiver support, home and community-based Medicaid waivers, assistive technology, transition services and supported employment.

Indiana Department of Health – Children’s Special Healthcare Services (CSHCS)
www.in.gov/isdh/19613.htm
Provides supplemental medical coverage to help families of children who have serious, chronic medical conditions, ages birth to 21, who meet the program’s financial and medical criteria.

Indiana Family and Social Services Administration – Division of Mental Health and Addiction
www.IN.gov/fssa
Information hub for Indiana’s mental health services for children and adults.

Indiana Protection and Advocacy Services
www.in.gov/ipas
Agency that assists families to secure appropriate medical, psychiatric or rehabilitation services for their children with disabilities and to assist in securing free and appropriate public education services for children with disabilities.

Community Resources

About Special Kids, Inc. (ASK), formerly the Indiana Parent Information Network, Inc. (IPIN)
www.aboutspecialkids.org
A "Parent to Parent" organization that works throughout the state of Indiana to answer questions and provide support, as well as information on the various systems related to special needs.

Indiana Resource Center for Families with Special Needs – IN*SOURCE
www.insource.org
Parent Training and Information Center, parent to parent mentoring and other programs to educate parents on special education processes and other disability topics.

Indiana Institute on Disability and Community – Center for Disability Information and Referral
www.iidc.indiana.edu/index.php?pageid=34
Information and resources for people with disabilities, their families and professionals.
IOWA

State Agencies

Iowa Medicaid Enterprise
www.ime.state.ia.us
Information hub for the Iowa Medicaid program, including the Medically Needy program, which offers partial payment for medical services to higher income families who apply through their local DHS office.

Iowa Department of Education – Special Education
www.state.ia.us/educate
Information hub for Iowa’s Special Education programs and services including links to Parent Information, Conflict Resolution, etc.

Hawk-I
www.hawk-i.org
Iowa’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Iowa Department of Human Rights – Division of Persons with Disabilities
www.state.ia.us/government/dhr/pd/index.html
Iowa Client Assistance Program (ICAP) offers assistance to individuals seeking or receiving services from the Division of Vocational Rehabilitation Services, Projects with Industry, or Independent Living Programs.

Iowa Department of Human Services – Home and Community-Based Services
www.ime.state.ia.us/HCBS/HCBSindex.html
Link to Medicaid page and interactive map of local DHS offices where one applies for services.

Iowa Vocational Rehabilitation Services
www.ivrs.iowa.gov
Agency that administers the Disability Determination Services Bureau (DDS) and the Rehabilitation Services Bureau. DDS determines eligibility for SSI.

Community Resources

Access for Special Kids Family Resource Center (ASK)
www.askresource.org
ASK Resource Center provides a broad range of information and advocacy including parent to parent coaching, healthcare coordination, and referrals to community-based services.

Iowa COMPASS
www.iowacompass.org
Iowa COMPASS is Iowa’s free, statewide information and referral service for people with disabilities, their families, service providers, and other members of the community. Offers trainings in disability awareness and classified ads for used assistive technology.

Iowa Program for Assistive Technology (IPAT)
www.uiowa.edu/infotech
IPAT operates an information and referral service for assistive technology called InfoTech to help callers find resources for new and used assistive technology and funding.

Iowa Protection and Advocacy Services, Inc.
www.ipna.org
Specialized team of disability advocates knowledgeable in training parent advocates and obtaining services in special education.
KANSAS

State Agencies

Kansas Medical Assistance Program – Medicaid
www.kmap-state-ks.us
Overview of the Kansas Medicaid program, eligibility rules and enrollment assistance.

Kansas State Department of Education – Special Education Services
Information hub for Kansas’ Special Education Programs, including a link to the Parents Guide to Special Education.

Kansas HealthWave
www.kansashealthwave.org
Kansas’ Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Kansas Department of Social and Rehabilitation Services
www.srskansas.org/services.htm
Complete index of services offered by the agency including disability determination, community-based services, mental health services, Medicaid, etc.

Make a Difference Information Network
www.makeadifferenceks.org
The Make a Difference Information Network (MADIN) is a collaborative effort among the Kansas Department of Health and Environment, the Kansas State Board of Education, the Kansas Department of Social and Rehabilitation Services, and Oral Health Kansas to connect Kansans with resources and services for individuals with disabilities.

Community Resources

Assistive Technology for Kansans Project (ATK)
http://atk.ku.edu
ATK helps persons with disabilities find ways to live and work independently through the use of assistive devices and services. Guidance on supported/sheltered work and for obtaining assistive technology through five regional Assistive Technology Access Sites.

Disability Rights Center of Kansas (DRC)
www.drckansas.org
Provides disability rights advocacy for consumers to general medical services including Medicaid, Medicare, long-term care, mental health services, and home and community-based services.

Families Together, Inc.
www.familiesgogetherinc.org
Serves families of children and youth with exceptional needs through four regional centers. Programs include the Parent Training and Information Center, Family to Family Health Information Center and the Parent to Parent support program.
KENTUCKY

State Agencies

Cabinet for Health and Family Services – Department for Medicaid Services
www.chfs.ky.gov/dms/default.htm
Entry point for Kentucky’s Medicaid program including links to covered services and enrollment procedures.

State Department of Education: Special Education
http://www.education.ky.gov/KDE/Instructional+Resources/Exceptional+Children/default.htm
Information hub for Kentucky’s Special Education programs with links to Parent Involvement, Dispute Resolution and Forms and Documents.

Kentucky Children’s Health Insurance Program
kidshealth.ky.gov/en/kchip
Kentucky’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Kentucky Cabinet for Health and Family Services – Department for Behavioral Health, Developmental and Intellectual Disabilities
www.mhmr.ky.gov/mhsas/ofl.asp
Family Leadership (OFL) webpage offers links to children’s service coordinators by county. Focus is primarily on mental health services.

Kentucky Cabinet for Health and Family Services – Commission for Children with Special Healthcare Needs
www.chfs.ky.gov/ccshcn/About.htm
Information on clinical programs available to children needing special medical care who meet financial guidelines.

Community Resources

Kentucky Special Parent Involvement Network KY-SPIN
http://www.kyspin.com
Parent Training and Information project that promotes self advocacy through a Family to Family training model. Resource guide, workshops and advocates available. Offers a transition program for young people, ages 14–21, who are non-diploma bound.

The Family Information Network on Disabilities – FIND of Louisville
http://www.findoflouisville.org
Provides information, training, referral, and advocacy to parents of children with disabilities and special needs, birth to age 26, and all disabilities (i.e. physical, cognitive, behavioral, and emotional).
LOUISIANA

State Agencies

Louisiana Health Services Financing – General Medicaid
www.dhh.louisiana.gov/offices/page.asp?id=92&detail=4125
Louisiana’s Medicaid program for persons under age 19 with disabilities. Includes links to application and printable flyer on services and eligibility.

Louisiana Department of Education – Special Populations
http://www.doe.state.la.us/lde/eia/2826.html
Information hub for Louisiana’s Special Education programs and a link to an Access Guide.

LaCHIP Processing Office
www.dhh.state.la.us/offices/?ID=119
Louisiana’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

The Office for Citizens with Developmental Disabilities (OCDD)
http://www.dhh.louisiana.gov/offices/page.asp?ID=77&Detail=3255
Overview of Louisiana’s support and services for persons with disabilities. Office that conducts disability determinations for purposes of SSI and Medicaid Home and Community-based Waiver programs. Services provided through 9 regional offices that can be found on the Waiver Supports and Services webpage.

Louisiana Department of Health and Hospitals – Office of Mental Health
http://www.dhh.louisiana.gov/offices/locations.asp?ID=62
Services locator by parish including 24-hour emergency mental health services.

Community Resources

The Advocacy Center
www.advocacyla.org
The Advocacy Center has a staff of lawyers, paralegals, client advocates and support staff who assist persons with disabilities to obtain appropriate education and to access public benefits through resources and referrals.

Louisiana Parent Training and Information Center (LaPTIC)
http://www.laptic.org/index.php
Louisiana Parent Training and Information Center provides information, referrals, and assistance to parents of children with disabilities through individual consultations by phone, email, and in person. Also provides in person support at meetings such as IFSPs, IEPs, and ITPs and parent trainings.

Pyramid Community Parent Resource Center
www.pyramidparentcenter.org
Assistance for New Orleans parents of children with disabilities in the areas of special education and positive behavior support at school through workshops and trainings.
MAINE

State Agencies

Maine Department of Health and Human Services – Office of Maine Care Services
www.maine.gov/dhhs/oms/member_index.html
Information hub for Maine’s health insurance program (formerly Medicaid) with links to care options, applications, member handbook, covered services and special eligibility options (waiver programs). Site includes Maine’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Maine Department of Education: Special Education
http://www.maine.gov/education/speced/index.htm
Overview of Maine’s Special Education programs, rules and due process regulations.

Maine Office of the Department of Health and Human Services
Child and Family Services – Children’s Behavioral Health Services
www.maine.gov/dhhs/ocfs/cbhs
Provides information and referrals for children to their 21st birthday. Includes crisis hotlines, links to county offices and evaluation sites, and eligibility information.

Community Resources

ALL-TECH
www.alltech-tsi.org
A nationally recognized center that provides training, consultation, resources, and technical assistance in the areas of assistive technology, specialized software, Web accessibility, etc. Assists in identifying and funding technological solutions to many of the educational, daily living, communication, and workplace issues presented by disabilities.

C.A.R.E.S., Inc
www.caresinc.org
Client Assistance Program that provides information, assistance and advocacy to people with disabilities who are applying for or receiving services, including Vocational Rehabilitation, Independent Living Services and Projects with Industry.

Maine CITE
www.mainecite.org
Coordinating center that helps Maine residents get, keep and use the assistive and universally designed technology they need.

Maine Disability Rights Center
www.maine.gov/dhhs/oes/resource/disab_rights.htm
Direct advocacy assistance, information and referrals, and training for persons with disabilities and their families.

Maine Parent Federation, Inc.
http://www.mpf.org
Statewide private non-profit organization that provides information, advocacy, education, and training. Links to Fact Sheets on special education topics including state resources, testing preparation, IEPS, supported employment, and others.

Pine Tree Society
http://www.pinetreesociety.org
Pine Tree Society helps young people in Maine with disabilities through case management, audiology, communication services, and community services.
MARYLAND

State Agencies

Maryland Medical Programs
www.dhmh.state.md.us/mma
Entry point for Maryland’s Medical Assistance Programs, including Medicaid, Home and Community-based Long Term Care, and the Children’s Health Insurance Program (CHIP) which offers affordable health insurance to youth and teens not eligible for Medicaid.

Maryland State Department of Education: Special Education and Early Intervention Services
www.marylandpublicschools.org/MSDE/divisions/earlyinterv
Coordinates support and information activities for families of children with disabilities from birth through age 21 through local Family Support Networks, Preschool Partners, and Partners for Success Resource Centers. Includes due process branch for special education mediation support.

Maryland Children’s Health Insurance Program (MCHP)
www.dhmh.state.md.us/mma/mchp
Maryland’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Maryland State Department of Health and Mental Hygiene: Developmental Disabilities Administration
www.ddamaryland.org
Information hub for Maryland’s Developmental Disabilities services, including disability determination services, waiver services and respite care, which are obtained through regional offices listed on the website under Services.

Maryland Department of Disabilities
www.mdtap.org
MDOD is the department that oversees Maryland’s disability benefits such as SSI and daily support services such as Healthcare, Mental Health Services, Personal Assistance Services, Pharmacy Assistance and Family Support.

Maryland State Department of Health and Mental Hygiene: Children’s Medical Services Program (CMS)
www.fha.maryland.gov/genetics/specialcare.cfm
Specialty care for low-income, uninsured or underinsured Marylanders, ages 0–21 years, with a chronic illness or disability. Family-centered, community-based systems of care, coordinated through county offices, listed under Specialty Care and Regional Resources Development.

Maryland State Department of Education – Division of Rehabilitation Services – Client Assistance Program
www.dors.state.md.us/DORS/ProgramServices/cap
Program that helps individuals who have concerns or difficulties when applying for or receiving rehabilitation services, including vocational rehabilitation, supported employment, and independent living.

Community Resources

The Coordinating Center (for individuals with complex medical needs and disabilities)
www.coordinatingcenter.org
Coordinates all services for individuals with complex medical needs through a Medicaid waiver program.

Family NET Works
http://www.family-networks.org/index.cfm
Online resource for disability-related information and support specific to the needs of Maryland families. Includes information on applying for services, parent mentors and training events.

Kennedy Krieger Institute
www.kennedykrieger.org
Organization with 35 outpatient clinics serving children and adolescents with disorders of the brain, spinal cord and musculoskeletal system and the Kennedy Krieger School which addresses the special education and related service needs of students, ages 6–21 years, who exhibit a wide range of learning, developmental and neurological disorders.
Maryland Disability Law Center  
www.mdlcbalto.org  
Advocates who assist in getting Disability, Medicaid and Special Education benefits.

The Parents’ Place of Maryland  
www.ppmd.org/index.asp  
A Parent Training and Information Center helping families of children with disabilities across the state of Maryland.

Transition to Adult Healthcare Self Advocacy Project  
www.resourcefinder.kennedykrieger.org/pdfs/mentor.pdf  
A mentor/mentee program designed for youth, ages 14 years through 25 years with developmental disabilities and other special healthcare needs, who are interested in understanding their diagnosis and controlling their healthcare.
MASSACHUSETTS

State Agencies

Massachusetts Office of Health and Human Services
www.mass.gov
Information hub for Massachusetts’ government services, including Medicaid, special education, healthcare, disabilities and more, found under “Residents” tab.

Massachusetts Office of Health and Human Services – Medicaid and MassHealth
www.mass.gov/?pageID=eohhs2constituent&L=2&L0=Home&L1=Consumer&sid=Eeohhs2
Entry point for Massachusetts's combined Medicaid and Children's Health Insurance Program (CHIP) – MassHealth.

Massachusetts Department of Elementary and Secondary Education: Special Education
www.doe.mass.edu/sped
Information on Massachusetts's Special Education programs with links to IEP forms and notices, mediation and appeals, and other resources.

Department of Developmental Services – Children
www.mass.gov/?pageID=eohhs2homepage&L=1&L0=Home&sid=Eeohhs2
Services and support for children with developmental disabilities. Information found in menu under Consumers, then Disability Services.

State Mental Health Representative for Children and Youth
www.mass.gov/?pageID=eohhs2homepage&L=1&L0=Home&sid=Eeohhs2
Services and support for children with behavioral health issues. Information found in menu under Consumers, then Behavioral Health.

Home Modifications Loan Program (HMLP)
www.mass.gov/?pageID=eohhs2homepage&L=1&L0=Home&sid=Eeohhs2
No – and low-interest loans to modify the homes of adults and children with disabilities. Includes program description, provider agencies and eligibility requirements. Information found in menu under Consumer, then Disability Services, then Housing.

Community Resources

The Federation for Children with Special Needs
www.fcsn.org/index.php
The Federation is a center for parents and parent organizations to work together on behalf of children with special needs and their families. Incorporates a Parent Training and Information Center for Massachusetts’ parents of disabled children, provides free, personalized advocacy, information and technical assistance related to special education law, community resources and more.

Family TIES of Massachusetts
www.massfamilyties.org/index.php
Parent-to-parent support, information and referral services, and workshops on topics from Early Intervention through transition to adulthood. Sections on transition services and a mental health how-to guide. Found in Regional Offices of the Massachusetts Department of Public Health.

Massachusetts Families Organizing for Change
www.mfofc.org/index.html
The mission of MFOFC is to provide sustained advocacy and leadership training in pursuit of high quality, individualized community support and service options, including family support for people with disabilities and their families.

MassMatch
www.massmatch.org
State assistive technology program with links to ads for used equipment, regional training centers and alternative financing programs.
New England INDEX
www.disabilityinfo.org
Extensive index of resources for people with disabilities maintained by the Shriver Center of UMASS Medical School. Includes an “Ask Index” feature for information requests.
**MICHIGAN**

**State Agencies**

**Michigan Office of Community Health – Medicaid**
www.michigan.gov/mdch/0,1607,7-132-2943_4860---,00.html
Entry point for Michigan's Medicaid program, including links to covered services and enrollment procedures.

**Michigan Department of Education – Special Education and Early Intervention Services**
http://www.michigan.gov/mde/0,1607,7-140-6530_6598---,00.html
Links to administrative forms and procedures, assessment, due process, etc. are found in the left column under Offices/ Special Education and Early Intervention Services.

**Michigan Department of Community Health – MIChild**
www.michigan.gov/mdch/0,1607,7-132-2943_4845_4931---,00.html
Michigan's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

**Michigan Department of Community Health – Mental Health and Developmental Disability**
www.michigan.gov/mdch/0,1607,7-132-2941_4868_4897---,00.html
Michigan's services to persons with developmental disabilities are provided through local Community Mental Health Service Programs (CMHSPs). Link to local resource locater.

**Michigan Department of Community Health – Children's Special Health Care Services (CSHCS)**
www.michigan.gov/mdch/0,1607,7-132-2942_4911_35698-15087--.00.html
Provides specialty medical services, family center services and community-based services to help disabled children and adults remain in their homes. Link to local offices which establish the qualifying medical condition and administer the services.

**Michigan Department of Community Health – Children with Special Needs Fund**
http://www.michigan.gov/mdch/0,1607,7-132-2942_4911_35698-56806--.00.html
Provides partial or full funding for wheelchair ramps into homes, van lifts and tie downs, air conditioners, and therapeutic tricycles. Link to application.

**Community Resources**

**Association for Children's Mental Health**
www.acmh-mi.org
Association that advocates for appropriate services for children and youth with emotional and behavioral disorders. Works in partnership with the Department of Community Health, Family Independence Agency, Community Mental Health Authorities, Family Court, the Department of Education and local school districts.

**Center for Educational Networking**
www.cenmi.org/matr
Special Education rules and facts, Directory of Service Providers for Infants, Toddlers, and Students With Disabilities, links to Michigan organizations serving students with disabilities including organizations that provide assistive technology.

**Citizens Alliance to Uphold Special Education (CAUSE)**
www.causeonline.org
Parent Training and Information Center (PTI) on special education issues.

**Michigan Alliance for Families**
www.michiganallianceforfamilies.org
Information, support and education for families of children and adults with disabilities from birth to age 26. Provides information, support and resources at regional sites to increase the involvement of parents in decisions about their children's education.

**Michigan’s Assistive Technology Program**
www.copower.org/AT/index.htm
Device demonstrations, training and low or no interest loan programs.
Michigan Association for Children with Emotional Disorders
www.michkids.org
Helps families find educational, mental health, and other services for teens with emotional and behavioral disorders.

Michigan Protection and Advocacy Service, Inc.
www.mpas.org
Assistance with obtaining Social Security benefits, Medicaid, Medicare and other insurance, Vocational Rehabilitation and other issues for persons with disabilities.

Michigan Special Education Mediation Program
www.cenmi.org/msemp
Facilitation and mediation services for the special education process including eligibility for services, evaluation results and IEP team meetings.
**State Agencies**

**Minnesota Department of Human Services – Medical Assistance (Medicaid)**
Entry point for Minnesota's Medicaid program including links to covered services and enrollment procedures.

**Minnesota Care**
Minnesota's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

**Minnesota Department of Human Services – Minnesota Healthcare Programs Children with Disabilities**
Information about Minnesota's healthcare programs for children with disabilities including TEFRA and waiver programs.

**Minnesota Department of Health – Children with Special Health Needs (MCSHN)**
[www.health.state.mn.us/mcshn](www.health.state.mn.us/mcshn)
Links to medical and rehabilitative assessments and services available in local communities.

**Community Resources**

**Courage Center**
[www.couragecenter.org](www.couragecenter.org)
Organization which offers occupational and physical therapy, vocational rehabilitation and more to children and youth with disabilities. Also offers accessible sports and recreation programs.

**PACER Center, Inc.**
[www.pacer.org](www.pacer.org)
Parent Training and Information Center offering parent to parent mentoring, resources and online training programs. Part of the national Pacer Center organization.
MISSISSIPPI

State Agencies

Mississippi Division of Medicaid
www.medicaid.ms.gov
Information hub for Mississippi’s Medicaid programs, including the Children’s Health Insurance Program (CHIP), Disabled Child Living at Home Program, and Home and Community-based Waiver Programs.

Mississippi Department of Education – Office of Special Education – Just for Parents
www.mde.k12.ms.us/special_education/just_for_parents.html
Articles and publications explaining Mississippi’s special education programs and procedures.

Mississippi’s Children’s Health Insurance Plan (CHIP)
www.msdh.state.ms.us/msdhsite/_static/41,0,96.html
Mississippi’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Mississippi Department of Mental Health – Developmental Disabilities
http://www.dmh.state.ms.us/mental_retardation.htm
Links to programs for children with developmental disabilities. Services and program locations outlined in the Intellectual and Developmental Disabilities State Plan which can be accessed from that website.

Mississippi State Department of Health: Children’s Medical Program
www.msdh.state.ms.us/msdhsite/_static/41,0,163.html
Organizes pediatric specialty care, physical/occupational therapy, durable medical equipment, etc. for disabled children to age 20, through pediatric social workers at local health departments. Eligibility requirements listed.

Community Resources

EMPOWER Community Resource Center
www.msempower.org
Parent Training Center on special education issues. Information and workshops about the range of options, programs, services, and resources available at the national, state, and local levels for children with disabilities and their families.

Mississippi Family as Allies for Children Mental Health, Inc.
http://www.msfaacmh.org
Information, services and emotional support to families and youth with mental health issues. Toll free crisis line, family respite services and more listed under Programs & Services.

Mississippi Protection and Advocacy System
www.mspas.com
Protection and advocacy for individuals with developmental disabilities in the areas of education, employment, housing, denial of services or denial of access.

Mississippi Society for Disabilities
www.msdisabilities.com
Client assistance in the area of vocational rehabilitation. Program provides physical, occupational and speech-language therapies. Offers a Specific Assistance Program to help pay for assistive aids, travel to out of town specialists, and assisted recreation.

Parents United Together
http://www.parentunitedtogether.com
Parent Training and Information Center offering information and support groups for disability issues.
MISSOURI

State Agencies

Missouri Department of Social Services – MO HealthNet for Kids
www.dss.mo.gov/mhk/index.htm
Portal to Missouri’s medical services programs, including MO HealthNet (Medicaid), and the State Children’s Health Insurance Program (SCHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Department of Elementary and Secondary Education – Special Education
www.dese.mo.gov/divspeced/parentresources.html
Information about Missouri’s Special Education program and resources for parents.

Missouri Department of Mental Health – Division of Developmental Disabilities FAQs
www.dmh.mo.gov/mrdd/new/consumer1.htm
Information about services provided to persons with developmental disabilities. Links to regional office locations where applications are accepted and processed.

Department of Health and Senior Services: Children with Special Healthcare Needs
www.dhss.mo.gov/SHCN/CSHCN.html
Preventive, diagnostic and treatment services for children and youth with disabilities, coordinated through 13 regional offices. Services include physical, occupational and speech therapies.

Community Resources

Missouri Parents Act: MPACT
http://ptimpact.org/About/About.aspx
Parent Training and Information Center on special education issues. Offers online resources and training events at regional locations.

Missouri Protection and Advocacy Services
www.moadvocacy.org
Assistance in obtaining services for persons with disabilities in the areas of Special Education and SSI, among others.

Sharing Our Strength: SOS
www.sharingourstrengths.com
Parent to parent mentoring and support network for parents of children with developmental disabilities or special healthcare needs.
MONTANA

State Agencies

Montana Department of Public Health & Human Services – Medicaid
www.dphhs.mt.gov/programsservices/medicaid.shtml
FAQs, eligibility and qualifying information, applications and forms.

Montana Office of Public Instruction – Children with Special Needs
www opi.state.mt.us
Portal to Montana’s Special Education programs, in the top menu under Parents, then Special Needs.

Montana Children’s Health Insurance Program (MCHIP)
www.chip.mt.gov
Montana’s Children’s Health Insurance Program (CHIP) which offers affordable health and dental insurance for children and teens not eligible for Medicaid.

Montana Department of Public Health & Human Services – Developmental Disabilities
www.dphhs.mt.gov/dsd
Links to information on Programs, Services, and Disability Determination Services. Regional/County office locator is found under Contact Us in the top menu bar.

Montana Department of Public Health & Human Services – Children’s Mental Health
Mental health services for children under age 18 provided through Medicaid, MCHIP, or the Supplemental Services Plan.

Montana Department of Public Health & Human Services – Children’s Special Health Services
Access to pediatric specialty clinics and other services for children with disabilities. Eligibility and application information found under Financial Assistance in the left column menu.

Community Services

Disability Rights Montana
www.disabilityrightsmt.org
Assistance for persons with disabilities to obtain services in the areas of special education, care and treatment, assistive technology and government benefits such as Medicaid and SSI.

Parents, Let’s Unite For Kids (PLUK)
www.pluk.org
Parent Training and Information Center offering information, resources and training to parents of children with disabilities.

The University of Montana Rural Institute: Transition Project
http://ruralinstitute.umt.edu/transition/default.asp
Transition services for youth with disabilities in rural areas of Montana. Includes supported and customized employment services.
NEBRASKA

State Agencies

Nebraska Department of Public Health & Human Services – Medicaid
www.hhs.state.ne.us/med/medindex.htm
FAQs, eligibility and qualifying information, applications and forms.

Nebraska Department of Education – Special Populations
www.nde.state.ne.us/SPED/sped.html
Information about Nebraska’s Special Education programs. Links to forms, mediation procedures and a Parent’s Rights Guide.

Kids Connection
www.hhs.state.ne.us/med/kidsconx.htm
Nebraska’s Children’s Health Insurance Program (CHIP) offers affordable health and dental insurance for children and teens not eligible for Medicaid.

Nebraska Department of Health and Human Services: Home and Community Services
www.hhss.ne.gov/hcs
Links to Nebraska’s programs and services for persons with disabilities including Disabled Medicaid Waiver, Disabled Children’s Program (DCP), Disabled Persons and Family Support Program, and the Medically Handicapped Children’s Program.

The Assistive Technology Partnership (ATP)
www.atp.ne.gov
Identification of assistive technology solutions and help in locating funding.

Nebraska Client Assistance Program
www.cap.ne.gov:3000/hotline_services
Information and referral for Nebraskans who have questions or concerns related to a disability.

Community Resources

Answers 4 Families
www.answers4families.org
A partnership of the Nebraska Department of Health & Human Services and the University of Nebraska, Lincoln’s Center on Children, Families, and the Law that offers expert information on Nebraska’s programs for children with special needs.

AT4ALL.COM
www.at4all.com
Quality used assistive technology – computers, wheelchairs & scooters, walkers, personal care items, etc.

Parent Training and Information Nebraska
www.pti-nebraska.org
Parent to parent mentoring, information and training for parents of children with disabilities in the area of special education.

Parent to Parent Network
www.parent-parent.org
Volunteer support groups for parents of children with disabilities throughout Nebraska.
NEVADA

State Agencies

Nevada Department of Public Health & Human Services – Division of Healthcare Financing and Policy – Medicaid
http://dhcfp.state.nv.us
FAQs, eligibility and qualifying information, applications and forms are found in the left column menu.

Nevada Department of Education: Special Education
http://nde.doe.nv.gov/SpecialEducation.htm
Information about Nevada’s Special Education programs. Parent’s Rights Guide is found in Special Education, then Resources, in the left column menu.

Division of Healthcare Financing and Policy – Nevada Check Up
www.nevadacheckup.state.nv.us
Nevada’s Children’s Health Insurance Program (CHIP) which offers affordable health and dental insurance for children and teens not eligible for Medicaid.

Nevada Department of Health and Human Services – Disability Services
http://dhhs.nv.gov/ODS_DisabilityServices.htm
Services for persons with physical disabilities including assistive technology, personal assistants, etc.

Children with Special Healthcare Needs (CSHCN)
www.health.nv.gov/CSHCN.htm
Portal to Nevada’s programs for children with disabilities with links to medical programs, Medicaid Waiver programs, school-based programs, parent support programs, etc.

Nevada Department of Health and Human Services – Division of Mental Health and Developmental Services
http://mhds.state.nv.us
Links to Nevada’s programs for persons with developmental disabilities found at the bottom of the page. Services delivered through three regional centers.

Project Assist
www.health.nv.gov/CSHCN_FindingResources_ProjectAssist.htm
Information source and database of resources for children and young adults with disabilities and their families. Call for a phone interview and a Project ASSIST staff person will send you a list of state and national programs and resources available for your family.

Community Resources

Disability Resources, Inc.
http://disabilityresourcesonline.org
Washoe County based non-profit organization that assists with supported employment and provides respite services.

Family TIES of Nevada
www.familytiesnv.org
Healthcare Information and Education Center that assists families of children with disabilities to understand and navigate health systems and insurance plans.

Nevada Disability Advocacy and Law Center
http://www.ndalc.org
Assistance for children and youth with disabilities to obtain special education and transition services.

Nevada PEP
www.nvpep.org/template.php?page=front
Nevada’s statewide Parent Training & Information Center for families of children with disabilities. Parent mentors and advocates are available to assist with special education issues.
NEW HAMPSHIRE

State Agencies

New Hampshire Department of Public Health & Human Services – Medicaid
www.dhhs.state.nh.us/DHHS/MEDICAIDPROGRAM/default.htm
FAQs, eligibility and qualifying information, applications and forms are found in the top menu bar.

New Hampshire Department of Education – Bureau of Special Education
http://www.ed.state.nh.us/education/doe/organization/instruction/bose.htm
Information and links to documents on New Hampshire’s Special Education programs.

Bureau of Developmental Services – Area Agencies
http://www.dhhs.state.nh.us/DHHS/BDS/support-agencies.htm
List of offices that coordinate services for children with developmental disabilities.

New Hampshire Healthy Kids
www.nhhealthykids.com
New Hampshire’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

New Hampshire Department of Education – Laws and Hearings/Mediation
www.ed.state.nh.us/education/laws/hearinginfo.htm
Link to Users Guide to Administrative Process and other information.

New Hampshire Department of Health and Human Services: Special Medical Services (SMS)
www.dhhs.state.nh.us/DHHS/SPECIALMEDSRVCS/sms-shc-children.htm
Specialty healthcare services for children with disabilities. Specialty clinics include therapy for neuro-motor disorders and speech and swallowing disorders.

Community Resources

Disabilities Rights Center, Inc.
www.drcnh.org
Information, referral, advice, and legal representation and advocacy for individuals with disabilities in the areas of special education, medical and financial assistance, etc.

Education-A-Must
www.education-a-must.com
Advocacy service that works with school districts and local, state & federal agencies to secure the necessary services and education for all who qualify.

Institute on Disability/UCED – Assistive Technology in New Hampshire – ATinNH
www.iod.unh.edu/technology.html
Help in obtaining assistive technology through equipment re-use, loans, and low cost funding alternatives.

The New Hampshire Challenge, Inc.
www.nhchallenge.org/about.asp
Offers news and information about disability issues and links to state agencies and local resources under the Find Help menu listing.

New Hampshire Family Voices
www.nhfv.org
Parent-run center that provides free technical assistance in navigating the maze of public and private services for children and youth with special healthcare needs.

Parent Information Center (PIC)
www.picnh.org
Parent Training and Information Center that offers parent to parent mentoring, training and information on special education issues.
The Parent Information Center on Special Education
http://www.nhspecialed.org
Information on New Hampshire’s special education laws, regulations and best practices.

Parent to Parent
www.p2pnh.org
Parent mentoring and support program.
NEW JERSEY

State Agencies

New Jersey Department of Human Services – Division of Medical Assistance & Health Services – Medicaid
www.state.nj.us/humanservices/dmahs/clients/medicaid
Eligibility and qualifying information. Links to county welfare offices where applications are processed.

Office of Special Education Programs
www.state.nj.us/education/specialed
Information and links to New Jersey’s Special Education programs.

New Jersey Family Care
www.njfamilycare.org
New Jersey’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

NJHelps
www.njhelps.org
Information about qualifying for 28 state and federal programs administered through the Department of Human Services and its partners in the areas of housing, employment, child care, health insurance, prescriptions, etc.

New Jersey Department of Human Services – Division of Developmental Disabilities
www.state.nj.us/humanservices/ddd/home
Information about New Jersey’s major programs and initiatives for persons with disabilities, including the Medicaid Community Care Waiver and Family Support Services for families caring for a disabled child.

New Jersey Department of Children and Families – Division of Child Behavioral Health Services
www.state.nj.us/dfc/behavioral
Access point for child and youth mental health services.

New Jersey Department of Health and Senior Services – Special Child Health Services
www.state.nj.us/health/fhs/sch/index.shtml
Assistance for families caring for children with complex, long-term medical and developmental disabilities. Link to Child Evaluation Centers where services are coordinated.

Community Resources

Association for Special Children and Families
www.ascfamily.org
Community organization offering training, resources and links for parents of children with disabilities.

Disability Rights New Jersey
www.drnj.org
Client Assistance Program offering information and referrals on a broad range of advocacy services including legal representation in the area of special education law. Includes the Assistive Technology Advocacy Center which assists people with disabilities to obtain assistive technology devices and/or services.

Family Support Center of New Jersey
www.fscnj.org
Clearinghouse for up-to-date information on national, state and local family support programs and services for disabilities.

New Jersey Statewide Parent-to-Parent
www.spannj.org/familywrap/parent2parent.htm
Statewide network of parents offering training, emotional support and information to families of children with developmental delays, disabilities, and special health needs.
Sparkle of UCP  
www.geocities.com/sparkleofucp  
Supportive resources for parents of children with disabilities including advocacy, information and referrals, and disability awareness presentations.

Statewide Parent Advocacy Network (SPAN)  
www.spannj.org  
Parent Training and Information Center (PTI) offering information specialists who assist parents in obtaining special education services and disability benefits, parent to parent support, and youth transition services.
NEW MEXICO

State Agencies

New Mexico Human Services Department – Medicaid
www.hsd.state.nm.us/mad/HMedicaid.html
Eligibility and qualifying information for New Mexico's Medicaid program. Online application and link to local Income Support Division (ISD) offices that determine eligibility.

New Mexico Department of Education: Special Education
www.ped.state.nm.us/seo/index.htm
Information and links to New Mexico's Special Education programs. Includes an “Especially for Parents” section with documents on special education topics.

Insure New Mexico Solutions – New MexiKids
www.insurenewmexico.state.nm.us/NewMexiKidsandTeens.htm
New Mexico's Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Community Resources

New Mexico Technology Assistance Program
www.nmtap.com
Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment recycling programs.

Parents Reaching Out
http://www.parentsreachingout.org
Parent Training and Information Center that offers workshops, trainings and parent mentors to help with issues related to special education and disability benefits. Includes extensive links to resources.

UNM Center for Development and Disability – Disability Resource Directory
http://cdd.unm.edu/infocenternm
New Mexico resources for persons with disabilities. Telephone referral specialists and online resource directory by area. Medicaid and state program tip sheets.
NEW YORK

State Agencies

New York State Department of Health – Medicaid
www.newyorkhealth.gov/health_care/medicaid/index.htm
FAQs, eligibility and qualifying information, applications and forms.

Vocational and Educational Services for Individuals with Disabilities (VESID)
http://www.vesid.nysed.gov
Website for all New York State special education and vocational programs. Information specifically for parents found in left column menu under Special Education, then Help for Parents.

Child Health Plus
New York State Health Department
www.health.state.ny.us/nysdoh/chplus/index.htm
New York’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

New York State Office of Mental Retardation and Developmental Disabilities
www.omr.state.ny.us/ws/index.jsp
Resource directory for New York’s major programs and initiatives for persons with disabilities. Statewide listing of not-for-profit voluntary agencies by region according to OMRDD’s Developmental Disabilities Services Offices (DDSO).

Office of Mental Health
www.omh.state.ny.us
Links to services for children and youth with emotional problems.

New York State Commission on Quality of Care and Advocacy for Persons with Disabilities
www.cqcapd.state.ny.us/aboutcqc/faqgen.htm
FAQs and resources for persons with disabilities who need advocacy to obtain special education services and disability benefits.

Community Resources

The Advocacy Center
www.advocacycenter.com/index.php
Links to Parent Training and Information Centers, special education advocates, service coordinators and other advocacy organizations.

Advocates for Children of New York (New York City)
www.advocatesforchildren.org
Citywide agency offering free individual case assistance to families and children who are experiencing problems in obtaining appropriate special educational services.

The Family Resource Network, Inc
http://www.familyrn.org
Parent Training and Information Center serving Broome, Chenango, Delaware, Otsego, Tioga and Tompkins Counties.

Resources for Children with Special Needs, Inc.
http://www.resourcesnyc.org/rhome3.php#
Help for families to understand and negotiate educational and human service systems in New York City.

Sinergia
www.sinergiany.org
Service coordination, information and support to individuals with disabilities in underserved families including many with limited English proficiency, African Americans, the homeless and families experiencing poverty.
United We Stand of New York  
http://www.uwsofny.org  
Community-based parent support program that serves culturally diverse families who have children with disabilities in Brooklyn and Red Hook.

Westchester Institute for Human Development  
www.wihd.org  
Programs and services in Westchester County. Includes dental services for persons with disabilities.
NORTH CAROLINA

State Agencies

North Carolina Division of Medical Assistance – Medicaid
www.ncdhhs.gov/dma/medicaid/index.htm
FAQs, eligibility and qualifying information, applications and forms.

Public Schools of North Carolina – Exceptional Children Division Parent Resources
www.ncpublicschools.org/ec/policy/resources
Handbook on Parent’s Rights and other information about North Carolina’s Special Education programs.

North Carolina Health Choice
www.dhhs.state.nc.us/dma/cpcont.htm
North Carolina’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

North Carolina Department of Health and Human Services – Services for People with Disabilities
www.ncdhhs.gov/disabilities/services.htm
Links to state programs for persons with disabilities including advocacy services and assistive technology programs.

North Carolina Client Assistance Program
http://cap.state.nc.us
Assistance to persons with disabilities in obtaining and maintaining employment.

North Carolina Department of Health and Human Services – North Carolina Assistive Technology Program
www.ncatp.org
Demonstrations, equipment loans, and funding sources for assistive technology.

North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services
www.ncdhhs.gov/mhddsas/consumers.htm
Information about North Carolina’s mental health services with links to local contacts and services. Downloadable consumer handbook.

Community Resources

Disability Rights North Carolina
www.disabilityrightscnc.org
Private organization that helps people across North Carolina to gain access to services and opportunities through advocacy and legal expertise.

Exceptional Children’s Assistance Center (ECAC, Inc.)
www.ECAC-parentcenter.org
Links to Parent Training and Information and Family Health Information Centers in North Carolina. Parent to parent mentoring, training and advocacy in the areas of special education and disability services.

First In Families of North Carolina
www.fifnc.org/index.html
Information, resources and support for low-income children and youth with disabilities. Services include recreational items, home furnishings or modifications, childcare or respite, repairs to vehicles, as well as support and training through local chapters.

F.I.R.S.T.
www.FIRSTwnc.org
Parent Training and Information Center serving Buncombe, Haywood, Henderson, Madison, Polk, Rutherford, Transylvania and Yancey Counties with training and advocacy in the areas of special education and disability services.
HOPE Parent Resource Center
www.fsnhope.org/index.php
Parent Training and Information Center that offers parents of children with disabilities training and advocacy in the areas of special education services. Parent to parent mentoring available.
NORTH DAKOTA

State Agencies

North Dakota Department of Human Services – Medicaid
www.nd.gov/dhs/services/medicalserv/medicaid
FAQs, eligibility and qualifying information, applications and forms.

North Dakota Department of Public Instruction: Special Education – Parent Resources
www.dpi.state.nd.us/speced/resource/parent/index.shtm
Overview of North Dakota’s Special Education programs including transition services.

Healthy Steps
www.nd.gov/dhs/services/medicalserv/chip
North Dakota’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

North Dakota Department of Human Services – Disability Services Division
www.nd.gov/dhs/services/disabilities
Links to Developmental Disabilities Services, Disability Determination Services, and rehabilitation and employment counseling.

North Dakota Department of Human Services – Mental Health Services
www.nd.gov/dhs/services/mentalhealth
Mental health and substance abuse services are delivered through eight Regional Human Service Centers and the North Dakota State Hospital in Jamestown.

North Dakota Department of Human Services – North Dakota Protection and Advocacy Project
http://www.ndpanda.org
Assistance and advocacy for persons with disabilities who are having difficulties accessing education services and disabilities benefits. Information and referrals in person and over the phone.

North Dakota Department of Human Services – Children’s Special Health Services – County Social Services
www.nd.gov/dhs/locations/countysocialserv
Interactive map for locating county social services offices, where applications can be made for Medicaid, children’s health services, community-based services and supports, etc.

North Dakota Department of Human Services – North Dakota Client Assistance Program
www.nd.gov/cap
Assistance for persons with disabilities to obtain and maintain employment.

North Dakota Interagency Program for Assistive Technology
www.ndipat.org
Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment recycling programs.

Community Resources

Pathfinder Family Center
www.pathfinder-nd.org
Parent Training and Information Center that offers parents of children with disabilities training and advocacy in the areas of special education services. Parent to parent mentoring available.
Ohio

State Agencies

Ohio Department of Job and Family Services – Medicaid
www.jfs.ohio.gov/ohp
FAQs, eligibility and qualifying information, applications and forms.

Ohio Department of Education – Students with Disabilities
www.ode.state.oh.us/GD/Templates/Pages/ODE/ODEPrimary.aspx?Page=2&TopicRelationID=967
Information and links to Ohio’s programs for students with disabilities.

Healthy Start Healthy Families
www.jfs.ohio.gov/OHP/consumers/familychild.htm
Ohio's Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Ohio Department of Mental Retardation & Developmental Disabilities
www.mrdd.ohio.gov
Portal for obtaining services for persons with disabilities.

Ohio Department of Health – Bureau for Children with Medical Handicaps
www.odh.ohio.gov/odhprograms/cmh/cwmh/bcmh1.aspx
State run network of healthcare providers for children with medical handicaps and programs to pay for services. Services administered through DOH offices in each county.

Ohio Department of Mental Health
www.mh.state.oh.us
Links to local mental health services.

Ohio Legal Rights Service
http://olrs.ohio.gov
Advocacy and referrals for persons with disabilities who are having difficulties obtaining special education services and disability benefits.

Community Resources

Assistive Technology of Ohio
www.atohio.org
Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment recycling programs.

Memorial Inc.
www.memorialinc.org
Educational and advocacy services for families of children with disabilities in the Cincinnati area.

The Ohio Coalition for the Education of Children with Disabilities (OCECD)
http://www.ocecd.org/ocecd/about/index.cfm
Assistance for parents of children with disabilities in navigating special education programs. Parent to parent mentoring, trainings and conferences offered.

Special Education Services (SES)
http://www.idealaw.org/Welcome.html
No cost legal advocacy in the area of special education for income eligible families. Assistance with IEP development, attendance at meetings, referrals to available community services.

Tools for Today and Tomorrow
http://www.tooldsfortoday.org
Information and support for parents of children with disabilities in or near Cuyahoga County.
OKLAHOMA

State Agencies

Oklahoma Healthcare Authority – Sooner Care (Medicaid and CHIP)
http://www.okhca.org
Enrollment and eligibility requirements for Oklahoma's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid and Oklahoma's Medicaid.

Oklahoma State Department of Education: Special Education Services
www.sde.state.ok.us/Curriculum/SpecEd/Resources_Parents.html
Resources for parents of children utilizing Oklahoma's Special Education programs.

Oklahoma Department of Human Services – Programs and Services for Persons with Disabilities
www.okdhs.org/programsandservices/docs/disabilities.htm
Entry point for services for persons with disabilities including SSI and TEFRA.

Oklahoma Department of Mental Health and Substance Abuse Services
www.odmhsas.org
Information and links to mental health services and hotlines.

Oklahoma Office of Disability Concerns – Client Assistance Program
www.odc.ok.gov/cap.html
Assistance for individuals with disabilities to obtain and maintain employment.

Oklahoma Statewide Community Resource Directory
www.join.ok.gov
Directory of services and programs available through the Oklahoma state government. Includes an eligibility questionnaire.

Community Resources

Oklahoma ABLE Tech
http://okabletech.okstate.edu
Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment recycling programs.

Oklahoma Disability Law Center, Inc.
www.oklahomadisabilitylaw.org
Legal advocacy and assistance in obtaining special education services.

Oklahoma Family Network
http://www.oklahomafamilynetwork.org/ofn
Oklahoma's statewide parent to parent mentorship and resource referral network that assists parents in obtaining special education services for their child with disabilities.

Oklahoma Parent Training and Information Center (PTI)
www.oklahomaparentscenter.org/About.html
Parent Training and Information Center assisting parents of children with disabilities in obtaining special education services.
OREGON

State Agencies

Oregon Health Plan – Medicaid and SCHIP
Enrollment and eligibility requirements for Medicaid and the Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Oregon Office of Learning Partnerships – Special Education
http://www.ode.state.or.us/search/results/?id=40
Information and links to Oregon's programs for students with disabilities.

Oregon Department of Human Services – Supports for Children with Developmental Disabilities
Information about services for children with developmental disabilities. Eligibility determined through local Community Developmental Disabilities Programs (CDDP). Link to local office locator.

Child and Adolescent Mental Health Services
www.oregon.gov/DHS/mentalhealth/index.shtml
Mental health services portal with links to children's services, publications and crisis services.

Community Resources

Access Technologies, Inc.
www.accesstechnologiesinc.org
Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment recycling programs.

Oregon Advocacy Center
www.oradvocacy.org
Assistance, legal advocacy and information about obtaining special education programs and disability benefits.

Oregon Families Information Referral Services and Training (Oregon FIRST)
http://www.orfirst.org
Community Parent Resource Center serving Washington, Multnomah and Clackamas Counties.

The Oregon Parent Training and Information Center
http://www.orpti.org
Parent Training and Information Center assisting parents of children with disabilities in obtaining special education services.
PENNSYLVANIA

State Agencies

Pennsylvania Department of Health and Human Services – COMPASS
www.dpw.state.pa.us
Online application for state benefits and services including Medicaid, CHIP, and Home and Community-based Services for persons with disabilities.

Pennsylvania Department of Public Welfare – Office of Medical Assistance Programs – Medicaid
www.dpw.state.pa.us/ServicesPrograms/MedicalAssistance
FAQs, eligibility and qualifying information, applications and forms. Local County Assistance Office locator provided.

Pennsylvania Department of Education: Special Education
http://www.pde.state.pa.us/special_edu/site/default.asp
Information and links to Pennsylvania’s programs for students with disabilities.

Pennsylvania’s Children’s Health Insurance Program
http://chipcoverspakids.com
Pennsylvania’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Pennsylvania Department of Public Welfare – Services for Persons with Disabilities
www.dpw.state.pa.us/ServicesPrograms/PhysicalDisabilities
Links to state programs for persons with disabilities. Local County Assistance Office locator provided.

Pennsylvania Department of Public Welfare – Mental Health Services
http://www.dpw.state.pa.us/ServicesPrograms/MentalHealthSubstanceAbuse/003676642.htm
Link to a county Mental Health/Mental Retardation office locator.

Community Resources

Disability Rights Network of Pennsylvania
www.drnpa.org
Information and advocacy for individuals with disabilities to access special education programs and disability benefits.

Hispanos Unidos para Ninos Excepcionales (Philadelphia HUNE, Inc.)
http://huneinc.org
Free bilingual (English and Spanish) training, technical assistance and individual assistance to parents of infants, toddlers, children, and youth with disabilities.

The Mentor Parent Program, Inc.
www.mentorparent.org

Parent Education Advocacy Leadership Center
http://www.pealcenter.org
Parent Training and Information Center assisting parents of children with disabilities to obtain special education services. Parent to Parent mentoring, advocacy and training.

P.E.N. – Parent Education Network
http://www.parentednet.org
Parent Training and Information Centers (PTIs), serving Philadelphia, North Central, South Central, Northeast, and Southeast Pennsylvania.

Parent to Parent of Pennsylvania
www.parenttoparent.org
Parent to parent mentoring for families of children and adults with disabilities.
Pennsylvania Client Assistance Program
www.equalemployment.org
Assistance to individuals with disabilities to obtain and maintain employment.

Pennsylvania’s Initiative on Assistive Technology
http://disabilities.temple.edu
Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment recycling programs.
PUERTO RICO

State Agencies

Estado Libre Asociado de Puerto Rico – Departamento de Salud – Medicaid
www.salud.gov.pr/Programas/ProgramaMedicaid/Pages/default.aspx
FAQs, eligibility and qualifying information, applications and forms.

Servicios a Niños con Necesidades Especiales de Salud
www.salud.gov.pr/programas/programamadresninosadolescentes/Pages/default.aspx
Services for children with neurological problems through multidisciplinary Pediatric Centers. List of local centers and contact information.

Departamento de Educación – Secretaría Asociada de Educación Especial
www.de.gobierno.pr/dePortal/Nuestro%20Departamento/Oficina%20del%20Secretario/SASEIPI/SASEIPI.aspx
Overview of Puerto Rico’s Special Education programs, including FAQs and parents’ rights.

Oficina Del Procurador De Las Personas Con Impedimentos
www.oppi.gobierno.pr
Assistance, legal advocacy and information to obtain special education programs and disability benefits.

Community Resources

Asociación de Padres Pro Bienestar de Niños con Impedidos de Puerto Rico, Inc. (APNI, Inc.)
www.apnipr.org
Parent Training and Information Center assisting parents of children with disabilities in obtaining special education services. Parent to Parent mentoring, advocacy and training.
RHODE ISLAND

State Agencies

Department of Health Services – Medical Assistance Program – Medicaid and Riteaid
www.dhs.state.ri.us/dhs/adults/dmadult.htm
Enrollment and eligibility requirements for Medicaid and Riteaid, Rhode Island’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

State Department of Education: Office of Special Populations
www.ride.ri.gov/Special_Populations/Default.aspx
Information and links to Rhode Island’s programs for students with disabilities.

Rite Care
www.dhs.state.ri.us/dhs/famchild/shcare.htm
Rhode Island’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Rhode Island Department of Health – Office of Special Healthcare Needs
www.health.ri.gov/family/specialneeds/resources.php
Information for parents on adolescent healthcare transition and other topics.

Rhode Island Department of Human Services – CEDARR Family Centers
www.dhs.state.ri.us/dhs/dcedarr.htm
CEDARR Family Centers (Comprehensive Evaluation, Diagnosis, Referral and Re-evaluation) offer families information and referrals to community support and assistance for their child with special needs.

Rhode Island Department of Human Services – Children with Special Needs
www.dhs.state.ri.us/dhs/famchild/dchspec.htm
FAQs and information about services for children with special needs, including CEDARR Family Resource Centers and the Katie Beckett medical waiver program.

Community Resources

Family to Family of Rhode Island
www.rifamilytofamily.net
Information, resources and support from other families of children with disabilities.

Family Voices of the Rhode Island Parent Information Network
www.ripin.org
Parent Training and Information Center assisting parents of children with disabilities in obtaining special education services and disability benefits. Parent to Parent mentoring, advocacy and training.

Parent Support Network of Rhode Island
www.psnri.org
Organization for parents of children and youth with serious behavioral, emotional, and/or mental health challenges.
SOUTH CAROLINA

State Agencies

South Carolina Department of Health and Human Services – Medicaid
www.dhhs.state.sc.us/dhssnew/beneficiaries.asp
Information about South Carolina's Medicaid program. FAQs, eligibility and qualifying information, applications and forms.

South Carolina Department of Education: Special Education
http://ed.sc.gov/topics/educationsupportsvcs/ec
Information about South Carolina's Special Education programs.

Healthy Connections Kids (SCHIP)
http://www.dhhs.state.sc.us/dhssnew/InsideDHHS/Bureaus/BureauofEligibilityProcessing/phc.asp?ProgramID=Benif
South Carolina's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

South Carolina Client Assistance Program
www.govoepp.state.sc.us/cap
Assistance to individuals with disabilities to obtain and maintain employment.

The South Carolina Department of Disabilities and Special Needs (DDSN)
www.ddsn.sc.gov/consumersandfamilies/default.htm
Information about services for South Carolinians with severe, lifelong disabilities. Includes Medicaid Waiver services.

South Carolina Department of Health and Environmental Control – Children's Rehabilitative Services
Statewide network of children's medical services, social work services, nutrition services, parent-to-parent support, physical, occupational and speech therapies, delivered at 8 Regional Public Health Office sites around the state.

South Carolina Department of Mental Health
www.state.sc.us/dmh/services.htm
Links to the state's mental health services and facilities.

Community Resources

Family Resource Center for Disabilities and Special Needs, Inc.
www.frcdsn.org
Support, training, information and referrals to families accessing special education services for their children and youth with disabilities in Charleston and throughout the Low Country.

PRO Parents
http://www.proparents.org
Parents Reaching Out to Parents (PRO) is a Parent Training and Information Center for families of children with special needs.

Protection and Advocacy for People with Disabilities, Inc.
www.protectionandadvocacy-sc.org
Information and resources to assist parents of children with disabilities in self-advocating for special education services and disability benefits. Investigates reports of school restraint and seclusion.

South Carolina Assistive Technology Program
www.sc.edu/scatp
Assistance in obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment recycling programs.
SOUTH DAKOTA

State Agencies

South Dakota Department of Social Services – Medicaid and CHIP
www.dss.sd.gov/medicaleligibility
Enrollment and eligibility requirements for Medicaid and South Dakota’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid. Link to Disabled Children’s Programs.

South Dakota Department of Education – Special Education Programs
www.doe.sd.gov/oess/specialed/Family/index.asp
Information for parents about South Dakota’s Special Education services.

South Dakota Department of Human Services – Division of Developmental Disabilities
www.dhs.sd.gov/dd
FAQs and links to programs and services for persons with developmental disabilities. Includes link to Disability Determination Services which includes information about expediting an SSI claim.

Department of Human Services – Division of Mental Health
http://dhs.sd.gov/dmh
Mental health services for children and adults provided through community mental health centers. Includes crisis intervention services and medication management.

Department of Human Services – Respite Care Program
www.dhs.sd.gov/dd/respite/index.aspx
Respite care program which pays for providers to care for children or adults with special needs while the caretakers take a class, go to a movie, go on vacation, or enjoy any activity. Respite care is available to eligible families regardless of income.

Community Resources

South Dakota Advocacy Services
www.sdadvocacy.com
Information and advocacy for individuals with disabilities to obtain special education services and disability benefits.

South Dakota Cares
www.southdakotacares.org
Access to assistive technology and medical equipment through the Recycle for Life program.

South Dakota Parent Connection, Inc.
http://www.sdparent.org/whoweare.html
Parent Training and Information Center assisting parents of children with disabilities to obtain special education services and disability benefits. Parent to Parent mentoring, advocacy and training.

South Dakota Parent Information and Resource Center
www.sdpirc.org
Parent Information and Resource Center assisting parents with support, training, information and referrals to special education services for their children and youth with disabilities.
TENNESSEE

State Agencies

State of Tennessee TennCare – Medicare
www.state.tn.us/tenncare
Information about Tennessee’s Medicaid program. Enrollment and eligibility requirements.

Tennessee Department of Education, Division of Special Education
www.state.tn.us/education/speced
Information about Tennessee’s Special Education services.

TENNderCARE
www.tn.gov/tenncare/tenndercare/index.html
Tennessee’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Community Resources

Disability Law & Advocacy Center of Tennessee (DLAC)
www.dlactn.org
Information and advocacy for individuals with disabilities in accessing special education programs and disability benefits. Online self-advocacy information library.

Disability Pathfinder
www.kc.vanderbilt.edu/tnpathfinder
Database of disability services and resources available in each Tennessee county. Telephone or email assistance navigating disability services. Developed by the John F. Kennedy Center for Research on Human Development at Vanderbilt University and the Council on Developmental Disabilities.

Support and Training for the Exceptional Parent
www.tnstep.org
Information, parent advocacy training, and support services to parents of children eligible to receive special education services.
TEXAS

State Agencies

Texas Health and Human Services Commission – Healthcare Coverage: Children and Youth
www.hhsc.state.tx.us/Medicaid/index.html
Enrollment and eligibility requirements for Children’s Medicaid and Texas’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

State Department of Education: Special Education
http://ritter.tea.state.tx.us/special.ed
Information about Special Education services. Includes links to parent’s rights documents, mediation services, the Texas Assistive Technology Network and more.

TexCare
www.texcarepartnership.com/CHIP-CHIP-Page.htm
Texas’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Texas Department of State Health Services – Children with Special Healthcare Needs (CSHCN) Services Program
www.dshs.state.tx.us/cshcn
Medical services for children who have exhausted all available Medicaid, CHIP and commercial health insurance benefits. Quick Link to Client Handbook.

Texas Department of Assistive and Rehabilitative Services – Disability Determination Services
http://www.dars.state.tx.us/services/dds.shtml
FAQs on Disability Determinations for Texans who apply for Social Security Disability Insurance and/or Supplemental Security Income. Applications are made at a local Social Security Office.

Community Resources

Advocacy, Inc.
www.advocacyinc.org
Technical assistance by private attorneys representing students with disabilities, development and dissemination of written materials for parents on a variety of education issues, and parent training on special education issues.

CDIC – Community Parent Resource Center
www.cdicelpaso.org
Community Parent Resource Center in El Paso offering information, parent advocacy training, and support services to parents of children eligible to receive special education services.

PATH Project
www.partnerstx.org
Parent Training and Information Center (PTI) serving Dallas, Fort Worth, Austin, Wichita Falls, Southeast and East Texas, assisting parents of children with disabilities in obtaining special education services and disability benefits. Parent to Parent mentoring, advocacy and training.

Partners Resource Network (PRN)
www.partnerstx.org
Partners Resource Network (PRN) is a non-profit agency that operates the statewide network of federally funded Parent Training and Information Centers (PTI’s) in Texas, assisting parents of children with disabilities in obtaining special education services and disability benefits. Parent to Parent mentoring, advocacy and training.

PEN Project
www.partnerstx.org
Parent Training and Information Center (PTI) serving Amarillo, Lubbock, Abilene, San Angelo, and El Paso, assisting parents of children with disabilities in obtaining special education services and disability benefits. Parent to Parent mentoring, advocacy and training.
Special Kids, Inc. (SKI)  
www.specialkidsinc.org  
Information, parent advocacy training, and support services to parents of children eligible to receive special education services in the Houston area. One on one consultations, support groups and parent trainings.

Team Project  
www.partnerstx.org  
Parent Training and Information Center (PTI) serving San Antonio, Houston, and the Lower Rio Grande Valley, assisting parents of children with disabilities in obtaining special education services and disability benefits. Parent to Parent mentoring, advocacy and training.

Texas Parent to Parent  
www.txp2p.org  
Information, parent advocacy training, and support services to parents of children eligible to receive special education services in the Austin/Rio Grande Valley areas. Parent to parent peer support, support groups and parent trainings.

Texas Project First  
www.texasprojectfirst.org  
Special education project of the Texas Education Agency, which provides accurate and consistent information and resources to students with disabilities and their families.
**State Agencies**

**Utah Department of Health – Utah Medicaid Program**  
www.health.utah.gov/medicaid  
Information about Utah’s Medicaid program. Enrollment and eligibility requirements.

**Utah Department of Education: Special Education**  
http://www.schools.utah.gov/sars  
Information on Utah’s Special Education services.

**Utah CHIP**  
www.utahchip.org  
Utah’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

**Utah Department of Human Services – Division of Services for People with Disabilities**  
http://www.dspd.utah.gov  
Home and community-based services for persons with disabilities, including community living, day services, supported employment services, and support for people with disabilities and their families. Program and Services links offers overviews and applications for services.

**Utah Department of Health – Community & Family Health Services (CFHS)**  
http://health.utah.gov/cfhs/aboutus.html  
Information about services for children with special healthcare needs. Includes Medicaid Waiver programs.

**Utah Center for Assistive Technology**  
www.usor.utah.gov:81/ucat  
Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment programs.

**Community Resources**

**Access Utah Network (Statewide Information and Referral for Disability Issues)**  
www.accessut.org  
Information and referral for individuals with disabilities. Telephone disability helpline and links to assistive equipment for sale.

**Disability Law Center**  
www.disabilitylawcenter.org  
Information and advocacy for individuals with disabilities in accessing special education programs and disability benefits.

**The Medical Home Portal**  
www.medicalhomeportal.org/?redirectDomain=true  
Assisting parents of children with disabilities to become effective partners in their care with physicians and other healthcare professionals.

**Utah Parent Center (UPC)**  
http://www.utahparentcenter.org  
Parent Training and Information Center (PTI) assisting parents of children with disabilities in obtaining special education services and disability benefits. Parent to Parent mentoring, advocacy and training.
**VERMONT**

**State Agencies**

Vermont Green Mountain Care  
[www.greenmountaincare.org](http://www.greenmountaincare.org)  
FAQs, information and application for programs such as Dr. Dynasaur (Vermont’s Children’s Health Insurance Program – CHIP), Vermont Health Access Plan (VHAP), and Medicaid, as well as the new Catamount Health. Low-cost and free health coverage programs for uninsured Vermonters.

Vermont Department of Education: Student Support Services – Parental Resources  
Provides information, resources and support to parents, guardians and families of children with disabilities.

Vermont Division of Disability and Aging Services – Department of Disabilities, Aging and Independent Living  
[www.ddas.vermont.gov](http://www.ddas.vermont.gov)  
Community-based long-term care services for individuals with developmental disabilities and physical disabilities. Includes Children’s Personal Care Services, Developmental Disability Services and the Choices for Care long-term care and Medicaid Waiver programs.

Vermont Agency of Human Services – Department of Disabilities, Aging and Independent Living – Vermont Assistive Technology Project  
[www.dail.state.vt.us/ATP](http://www.dail.state.vt.us/ATP)  
Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment programs.

Vermont Department of Health – Children with Special Health Needs (CSHN)  
[www.healthvermont.gov/family/cshn/cshn.aspx](http://www.healthvermont.gov/family/cshn/cshn.aspx)  
Information about state programs and services for children with complex medical conditions.

Vermont Department of Mental Health – Agency of Human Services  
[http://mentalhealth.vermont.gov/cafu](http://mentalhealth.vermont.gov/cafu)  
FAQs and information on Vermont’s mental health programs for children and youth.

**Community Resources**

Disability Law Project  
[www.vtlegalaid.org](http://www.vtlegalaid.org)  
Legal assistance for parents of children with disabilities to obtain special education services and disability benefits.

Parent-to-Parent of Vermont  
[www.partoparvt.org](http://www.partoparvt.org)  
Medicaid and SSI consulting. Parent to parent mentoring programs.

Vermont Family Network  
[www.vermontfamilynetwork.org](http://www.vermontfamilynetwork.org)  
Information and resources to assist parents of children with disabilities, ages birth thru 26 years, to effectively participate in their children's education, development, and transition to adult life.

Vermont Protection and Advocacy, Inc.  
[www.vtpa.org](http://www.vtpa.org)  
Assistance with obtaining special education services and disability benefits.
**VIRGINIA**

**State Agencies**

Virginia Department of Medical Assistance Services – Medicaid  
www.dmas.virginia.gov/rcp-home.htm  
FAQs and documents about Virginia’s Medicaid program, long term care and Waiver services, including eligibility for children under age 19.

Virginia Department of Education: Division of Special Education – Parent Resources  
www.doe.virginia.gov/VDOE/sped/parents.shtml  
FAQs and information for parents of children using special education services.

FAMIS  
www.famis.org  
Virginia’s Children’s Health Insurance program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services – How to Get Help  
wwwdbhds.virginia.gov/SVC-default.htm  
FAQs about programs for persons with developmental disabilities in Virginia. Link to Community Services Boards, which are portals to services.

Virginia Department of Health – Children with Special Healthcare Needs – Care Connection for Children (CCC)  
www.vahealth.org/specialchildren/cccprogram.asp  
Specialty medical services and medical insurance benefits evaluation for children with chronic health problems. Eligibility requirements and a map of service areas and CCC offices.

**Community Resources**

Medical Home Plus  
www.medhomeplus.org  
Organization offering an online Family Resource Center, Resource Referrals by phone, and Service Coordination to obtain special education services.

Parent Educational Advocacy Training Center (PEATC)  
http://www.peatc.org  
Parent Training and Information Center assisting parents of children with disabilities with information and support to obtain special education services.

Parent to Parent of Virginia  
http://www.ptpofva.com  
Programs to assist parents of children with disabilities to obtain special education services and disability benefits. Parent to Parent mentoring, advocacy and training.

Virginia Assistive Technology System (VATS)  
www.vats.org/aboutvats.htm  
Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment programs.
WASHINGTON

State Agencies

Washington Department of Health and Social Services – Health and Recovery Services Administration – Medicaid
www.adsa.dshs.wa.gov/pubinfo/benefits/medicaid.htm
Information about Washington’s Medicaid program. Enrollment and eligibility requirements.

State of Washington – Office of Superintendent of Public Instruction – Special Education
www.k12.wa.us/specialed
Information about Washington’s Special Education programs. Link to assessment information, dispute resolution, etc. Link to citizen’s representative – the Ombudsman.

Children’s Health Insurance Program (SCHIP)
http://hrsa.dshs.wa.gov/CHIP/Index.html
Washington’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Washington Department of Health and Social Services – Division of Developmental Disabilities (DDD)
www.dshs.wa.gov/ddd
Central information hub for DDD services, assessment procedures and waiver programs. Links to Washington’s mental health programs.

Washington Client Assistance Program
www.washingtoncap.org
Assistance for persons with disabilities who wish to work or continue working.

Community Resources

Families Together
www.familiestogether.org
Rural outreach serving Southeast Washington for families of children with disabilities. Support and information on advocacy for parents and nondisabled siblings.

Parent to Parent Power
http://p2ppower.org
Organization assisting Asian parents of children with disabilities to obtain special education services and disability benefits.

PROVAIL
www.provail.org
66 year-old organization that offers therapeutic and assistive technology services, dental clinic, employment services and employment opportunities in their Fabrication Division.

University of Washington School of Dentistry: Referral Services
www.dental.washington.edu/disability
Quick locator of dental resources for persons with disabilities.

Washington Assistive Technology Act Program
www.watap.org
Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment programs.

Washington PAVE
www.washingtonpave.org
Parent Training and Information Center (PTI) offering resources, training and support for parents of children with disabilities. Parent to parent mentoring.
**State Agencies**

West Virginia Department of Health and Human Resources – Bureau for Children and Families – Medicaid
www.wvdhhr.org/bms
Information about West Virginia’s Medicaid program. Online application. County office locator.

West Virginia Department of Education – Special Education – Parent Educator Resource Center
http://wvde.state.wv.us/osp/perc.html
Information for parents about West Virginia’s Special Education programs. Link to Parent Guide.

West Virginia CHIP
www.wvchip.org
West Virginia’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

West Virginia Bureau for Behavioral Health and Health Facilities – Division for Developmental Disabilities
www.wvdhhr.org/bhhf/mrdd.asp
Information about West Virginia’s programs for persons with developmental disabilities and their families including the Family Support program and Mental Health Crisis Services.

**Community Resources**

West Virginia Advocates
www.wvadvocates.org
Information to assist parents of children with disabilities in obtaining special education services, assistive technology and disability benefits.

West Virginia Parent Training and Information Project (WVPTI)
www.wvpti.org
Parent Training and Information Center (PTI) offering resources, training and support for parents of children with disabilities to obtain special education services and disability benefits. Parent to parent mentoring.
**Wisconsin**

**State Agencies**

**Wisconsin Department of Health Services – Medicaid**  
www.dhs.wisconsin.gov/medicaid  
Information about Wisconsin’s Medicaid program. Online enrollment forms and eligibility requirements.

**Wisconsin State Department of Education: Special Education**  
www.dpi.wi.gov/sped/hmparents.html  
Information for parents of children accessing Wisconsin’s Special Education programs.

**Wisconsin Department of Health Services – BadgerCare+**  
www.dhs.wisconsin.gov/BadgerCarePlus  
Wisconsin’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

**Wisconsin Department of Health Services – Children and Youth with Special Healthcare Needs Program**  
http://dhs.wisconsin.gov/health/children  
Services, including Medical Home Care, for children with chronic health conditions. Link to Wisconsin First Step searchable service database for children and youth with disabilities.

**Wisconsin Department of Health Services – Wisconsin’s Assistive Technology (WisTech) Program**  
http://dhs.wisconsin.gov/disabilities/wistech/index.htm  
Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment programs.

**Wisconsin Department of Vocational Rehabilitation – Client Assistance Program**  
www.wicap.wisconsin.gov/index.jsp  
Assistance for persons with disabilities to obtain and maintain employment.

**Community Resources**

**Family Voices of Wisconsin**  
www.wfv.org/fv  
Family Voices provides information, training and support around healthcare and community services for families and professional partners.

**MUMS – National Parent to Parent Network**  
www.netnet.net/mums  
Parent to parent support and mentoring program. Maintains a database to match parents by age, geographical local, gender and severity of the child’s disability.

**Parent to Parent of Wisconsin**  
www.p2pwi.org  
Parent to parent mentoring in the areas of special education services, healthcare and community services. Links to other organizations and resources.

**Wisconsin Family Assistance Center for Education, Training and Support (FACETS)**  
www.wifacets.org  
Parent Training and Information Center (PTI) offering resources, training and support for parents of children with disabilities in obtaining special education services and disability benefits. Parent to parent mentoring.
WYOMING

State Agencies

Wyoming Department of Health – Equality Care (Medicaid)
http://wdh.state.wy.us/healthcarefin/medicaid/eligibility.html
Eligibility and application information about EqualityCare, Wyoming’s Medicaid program. Downloadable Healthcare Coverage Application, which is also used for Kid Care CHIP. Link to District map of the Department of Family Services offices where applications are submitted.

Wyoming Department of Education – Special Education
www.k12.wy.us/se.asp
General information about Wyoming’s Special Education programs. Downloadable IEP and Dispute Resolution forms.

KidCare CHIP
http://wdh.state.wy.us/healthcarefin/chip/index.html
Wyoming’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Wyoming Department of Health – Mental Health and Substance Abuse – Children’s Waiver Program
www.health.wyo.gov/mhsa/treatment/waiverindex.html
Program for treating severe mental illness in a child or teen in their home communities with their parents/families involved in all aspects of their treatment.

Wyoming Department of Health – Children’s Special Healthcare Program
http://wdh.state.wy.us/familyhealth/csh/index.html
Downloadable brochure about Wyoming’s program for children with chronic health problems. Provides care coordination and support services.

Community Resources

Parent Education Network (PEN)
www.wpen.net
Parent Training and Information Center (PTI) offering resources, training and support for parents of children with disabilities to obtain special education services and disability benefits. Parent to parent mentoring.

Parent Information Center
www.wpic.org
Workshops and trainings for parents of children with disabilities for self advocacy in the area of special education.

Rehabilitation Enterprises of North Eastern Wyoming (RENEW)
www.renew-wyo.com
Assistance with a variety of supported employment opportunities for persons with disabilities.

Wyoming Protection and Advocacy System, Inc.
www.wypanda.com/programs.asp
Advocacy and assistance in obtaining special education and other services.
A Guide to HDSA's Chapters, Affiliates, Regions and Centers of Excellence

HDSA has placed professional staff in strategic locations across the country to provide assistance in fund raising, awareness, education and care initiatives offered by HDSA in support of HDSA's mission.

Regional Development Directors are responsible for the states listed including all chapters, affiliates and HDSA Centers of Excellence within that region. Regional Development Directors work directly with HDSA volunteers to maximize local resources and efforts in the care and cure of HD.

Information changes constantly. Please contact HDSA at 800-345-HDSA for updated information or go to the HDSA national web site at www.hdsa.org and click on “Find HDSA in your Community.”

HDSA National Field Development and Operations Director
Nancy Rhodes
HDSA National Office
Tel: 212-242-1968 or 800-345-4372

HDSA National Field Development and Operations Manager
Alex Roque
HDSA National Office
Tel: 212-242-1968 ext. 223
Email: aroque@hdsa.org

NEW ENGLAND REGION
(CT, ME, MA, NH, RI, VT)
Virginia Goolkasian
HDSA Regional Development Director
Tel: 978-256-0811 or (toll free) 888-554-8102
Email: vgoolkasian@hdsa.org

HDSA Chapters
Connecticut Affiliate
c/o Susan McGann
Tel: 860-558-8847
Email: smcgann@hdsa-ct.org

Maine Affiliate
c/o Raima Fernald
Tel: 207-283-4945
Email: raimajean@yahoo.com

New Hampshire Affiliate
c/o Charlene Weed
Tel: 603-742-1348
Email: weedswd@comcast.net

Massachusetts Chapter
c/o Virginia Goolkasian
HDSA Regional Development Director
www.hdsa-ne.org

GREATER NEW YORK REGION
(NY, NJ, Fairfield County, CT)
Chenell Tannure
HDSA Regional Special Events Coordinator
Tel: 212-242-1968 ext. 221
Email: ctannure@hdsa.org

HDSA Chapters
Long Island Affiliate
New York Metro Affiliate
c/o Chenell Tannure
New Jersey Chapter
c/o Christi Kobus Rokicki
Executive Director
Tel: 973-784-4965
www.hdsanj.com
crokicki@hdsa.org

Upstate New York Chapter
c/o Chenell Tannure
HDSA Regional Special Events Coordinator
212-242-1968 ext. 221
www.hdsauiny.org

MID-ATLANTIC REGION
(DE, PA, WVA, VA, MD, Wash DC)
c/o HDSA National Field Development and Operations Department
Tel: 212-242-1968 or (toll free) 800-345-4372
HDSA Chapters
Delaware Valley Chapter
c/o Susan Liberace
HDSA Chapter Executive Director
Tel: 610-260-0420
Email: sliberace@hdsa.org
www.dvhdsa.org

Delaware Chapter
Tel: 877-384-3721

Washington Metro Chapter
Tel: 703-204-4634
703-323-1403
http://www.dchdsa.org

Western Pennsylvania Chapter
Tel: 412-833-8180
888-779-HDSA (4372)
www.hdsawpa.org

SOUTHEAST REGION
(NC, SC, AL, GA, FL)
HDSA National Field Development and Operations Department
Tel: 212-242-1968 or (toll free) 800-345-4372

HDSA Chapters
North Carolina Chapter
c/o Worth Bolton
Tel: 919-389-9224
www.hdsanc.org

Georgia Chapter
Tel: 404-223-2294
www.hdsa-ga.org

Central Florida Affiliate
c/o Karen Milek
Tel: 407-719-2291

South Florida Chapter
Tel: 305-274-7411
www.huntingtonsdiseasefl.org

GREAT LAKES REGION
(MI, IN, OH, KY, WI, MO (St. Louis only)
c/o HDSA National Field Development and Operations Department
Tel: 212-242-1968 or (toll free) (800-345-4372

HDSA Chapters
Central Ohio Chapter
c/o Wendy Vaughan
Tel: 614-460-8800
866-877-HDSA (4372)
Email:wvaughan@hdsa.org
http://www.hdsacentralohio.org

Indiana Chapter
Tel: 317-271-0624 or (toll free) 866-488-0008
www.hdsaindiana.org

Kentucky Chapter
Tel: 502-637-4372
800-784-3721 (KY only)
Email: hdsakychapter@bellsouth.net

Michigan Chapter
Tel: 989-832-4170
800-909-0073
Email: hdsami@att.net
http://hdsa-mi.com

Northeast Ohio Chapter
c/o Barbara Kaiser
Tel: 330-998-6600
Email: Bkaiser@hdsa.org

Ohio Valley Chapter
Tel: 513-741-HDSA (4372)

St. Louis Chapter
c/o Peggy Cribbin
HDSA Chapter Executive Director
Tel: 314-647-HDSA (4372)
866-707-4372
Email: pcribbin@hdsa.org
www.hdsastl.org

Wisconsin Chapter
Tel: 414-257-9499
877-330-2699
www.hdsawi.org

SOUTHWEST REGION
(TX, OK, LA, MS, AR, KS, TN, MO (except St. Louis)
Janice Watsky
HDSA Regional Development Director
Tel: 504-712-0523 or 866-712-0523
Email: jwatsky@hdsa.org
HDSA Chapters

Oklahoma Chapter
Tel: 405-236-4372 or 877-232-4372
www.okhdsa.com
okhdsa@sbcglobal.net

Arkansas Affiliate
Tel: 800-536-1728 (pin no. 5935)
hdsa-arkansas@comcast.net

Texas Affiliate
Tel: 504-712-0523
www.hdsatexas.org

UPPER MIDWEST REGION
(ND, SD, NE, MN, IA, IL)
Leigh Peterson
HDSA Regional Development Director
Tel: 763-502-1407
Email: lpeterson@hdsa.org

HDSA Chapters

Illinois Chapter
Tel: 630-443-9876
www.hdsa-il.com

Iowa Chapter
Tel: 866-248-4243
712-542-4976
Email: mail@hdsaiowa.org

Minnesota Chapter
Tel: 612-371-0904
Email: hdsamn@hdsa.org
www.hdsa-mn.org

Sioux Valley Chapter
Tel: 605-334-9917

ROCKY MOUNTAIN REGION
(NM, UT, WY, AZ, CO)
Kendell Aitchison
HDSA Regional Development Director
Tel: (303) 837-9937
E-mail: kaitchison@hdsa.org or
regional@hdsarockymountain.org

Rocky Mountain Chapter
c/o Kendell Aitchison
HDSA Regional Development Director
Tel: 303-321-5503 or 877-740-4372
www.hdsarockymountain.org

NORTHWEST REGION
(WA, OR, ID, MT)
HDSA National Field Development and
Operations Department
Tel: 212-242-1968 or (toll free) 800-345-4372

HDSA Chapters

Northwest Chapter
c/o Roxanne Harris
HDSA Special Events Coordinator
Tel: 206-464-9598
Email: nwhdsa@yahoo.com
www.nwhdsa.org

NORTHERN CALIFORNIA REGION
(No. CA, NV)
Penny Riley
HDSA Regional Development Director
Tel: 916-927-4400
Email: priley@hdsa.org
www.hdsanortherncaifornia.org

SOUTHERN CALIFORNIA REGION
(So. CA, S. NV)
c/o Natalie Carpenter
Tel: 619-225-2255
Email: ncarpenter@hdsa.org

HDSA Chapters:

Greater Los Angeles Chapter
tel: 888-4-HDSA LA
800-686-9868
Orange County Chapter
Tel: 866-920-0601
www.hdsaooc.org
San Diego Chapter
Tel: 800-473-4014
619-225-2255
www.hdsasandiego.org
HDSA SOCIAL WORKERS

HDSA social workers are located at all 21 HDSA Centers of Excellence and 17 HDSA Chapters. The list below is offered for informational purposes only.

Inclusion does not constitute an endorsement or recommendation by HDSA. Information changes constantly. Please visit the HDSA national web site for the most up to date contact information.

ALABAMA
HDSA Center of Excellence at the HD Clinic at the Children’s Hospital of Alabama
Birmingham, AL
Social Worker: Lynda Williams, MSW, LGSW
Tel: 205-939-9085
Email: lynda.williams@chsys.org

ARIZONA
Arizona Affiliate
Tempe, AZ 85282
Social Worker: Christina Bates, MC, LPC
Tel: 480-200-8595
Email: christinabates@cox.net

Arizona Affiliate
Tucson, AZ
Social Worker: Joan Jervis, LPC
Tel: 520-886-6063
Email: joanjervis@comcast.net

CALIFORNIA
HDSA Center of Excellence at University of California Davis Medical Center
Social Worker: Corey Lucero-Perkins
Tel: 916-734-6277
Email: coreen.lucero-perkins@ucdmc.ucdavis.edu

HDSA Center of Excellence at University of California
San Diego, CA
Social Worker: Lisa Snyder, MSW, LCSW
Tel: 858-622-5800
Email: lsnnyder@ucsd.edu

HDSA Center of Excellence at UCLA
Los Angeles, CA
Social Worker: Barbara Fallick, MSW
Tel: 310-794-1225
Email: BGf4231942@yahoo.com

CONNECTICUT
University of Connecticut Health Center
Huntington’s Disease Program
Farmington, CT
Social Worker: Bonnie Hennig, MSW, LCSW
Tel: 860-679-4441
Email: hennig@psychiatry.ucnh.edu

COLORADO
Center of Excellence at the Colorado Neurological Institute
Engelwood, CO
Tel: 720-974-4092

Rocky Mountain Chapter
Wheat Ridge, CO
Social Worker: Jan Jerome, LCSW
Tel: 720-371-5806
Email: socialworker@hdsarockymountain.org

DELAWARE
Delaware Valley Chapter
Plymouth, PA
Social Worker: Joanne Luz
Tel: 877-384-3721
Email: jluz@dvhdsa.org

FLORIDA
HDSA Center of Excellence at the University of South Florida
Tampa, FL
Social Worker: Lisa Bentivenga, MSW
Phone: 813-974-6022
Email: lbentive@health.usf.edu

GEORGIA
HDSA Center of Excellence at Emory School of Medicine
Atlanta, GA
Social Worker: Lynn Ross, LMSW
Tel: 404-728-6300
Email: sross@emory.edu

ILLINOIS
HDSA Center of Excellence at Rush University Medical Center
Chicago, IL
Social Worker: Marjorie Johnson, MSW, MFT
Tel: 312-563-2900
Email: Marjorie_G_Johnson@rush.edu

INDIANA
Chapter & Indiana University HDSA Center of Excellence
Indiana University School of Medicine
Indianapolis, IN
Social Worker: Leo Rafail, BSW
Tel: 866-488-0008
Email: info@hdsaindiana.org
IOWA
HDSA Center of Excellence at University of Iowa Hospitals and Clinics
Iowa City, IA
Social Worker: Anne Leserman, MSW, LISW
Tel: 319-353-4307
Email: anne-leserman@uiowa.edu

KENTUCKY
Kentucky Chapter
Louisville, KY
Social Worker: Cathy Saliga, LCSW
Tel: 502-637-4372
Email: hdsakychapter@bellsouth.net

MARYLAND
HDSA Center of Excellence at Johns Hopkins
Baltimore, MD
Social Worker: Catherine McFarlane, MSW
Tel: 410-955-2497
Email: cmcfarl1@jhmi.edu

MASSACHUSETTS
Chapter & New England HDSA Center of Excellence
Charlestown, MA
Social Worker: Judith Sinsheimer, LCSW
Tel: 617-726-2603
Email: jsinsheimer@partners.org
New England Social Worker
Social Worker: Eric St. Onge, MSW
Tel: 888-554-8102 ext. 12
Email: estonge@hdsa.org

MICHIGAN
Michigan Chapter
Dimondale, MI
Social Worker: Danny Berry, LBSW
Tel: 800-909-0073
Email: hdsamisw@gmail.com

MINNESOTA
Minnesota Chapter
Social Worker: Jessica Hancock, LSW
Tel: 612-371-0904 or 877-371-0904
Email: jhancoc1@good-sam.com
Center of Excellence at Hennepin County Medical Center
Minneapolis, MN
Social Worker: Nina Ross, LISW
Tel: 612-873-3369
Email: Nina.Ross@hcmmed.org

MISSOURI
Chapter & HDSA Center of Excellence at Washington University School of Medicine
St. Louis, MO
Social Worker: Stacey Barton, LCSW, MSW
Tel: 314-362-3471
Email: bartons@neuro.wustl.edu

NEW JERSEY
Huntington's Disease Family Service Center
Piscataway, NJ
Social Worker: Christine Hogan, LCSW
Tel: 732-235-5993
Email: hoganch1@umdnj.edu
Center for Aging
Stratford, NJ
Social Worker: Nancy M. Alterman, LCSW
Tel: 856-566-7078
Email: altermnm@umdnj.edu

NEW YORK
HDSA Center of Excellence at Columbia Health Sciences/ New York State Psychiatric Institute
New York, NY
Social Worker: Debbie Thorne, LCSW
Tel: 212-305-9172
Email: thorned@sergievsky.cpmc.columbia.edu
George C. Powell HDSA Center of Excellence at North Shore University Hospital
Great Neck, NY
Social Worker: Patricia Lambert, LCSW
Tel: 631-234-0136
Email: patalero@aol.com
HDSA Center of Excellence at University of Rochester
Rochester, NY
Social Worker: Amy Chesire, LCSW-R, MSG
Tel: 585-341-7519
Email: amy.chesire@ctcc.rochester.edu
OHIO
HDSA Center of Excellence at Ohio State University
Columbus, OH
Social Worker: Barbara Heiman, LISW
Tel: 614-292-9960
Email: barbheiman@juno.com
Ohio Chapter
Cincinnati, OH
Social Worker: Mary Beth Bialick, LISW
Tel: 513-741-4372
Email: howardb33@aol.com
Northeast Ohio Chapter
Social Worker: Kristin Zverloff MSW, LISW-S
Tel: 330-571-0545
Email: kitzmiller27kr@yahoo.com

PENNSYLVANIA
Delaware Valley Chapter
Plymouth, PA
Social Worker: Joanne Luz
Tel: 877-384-3721
Email: jluz@dvhdsa.org
Western Pennsylvania Chapter
Pittsburgh, PA
Social Worker: Peggy Polito, MSW
Tel: 888-779-4372
Email: pegpolito@aol.com

SOUTH DAKOTA
Sioux Valley Chapter
Sioux Falls, SD
Social Worker: Eileen Krueger, LSW
Tel: 605-693-6651 or 612-910-6651
Email: ekrueger@good-sam.com

TEXAS
HDSA Center of Excellence at Baylor College of Medicine
Houston, TX
Social Worker: Alicia Palao, MA
Tel: 713-798-7438
Email: palao@bcm.tmc.edu
Texas Chapter
Dallas, TX
Social Worker: Cheryl Lenheiser, LCSW
Tel: 800-910-6111
Email: txhd.socialworker@verizon.net

VIRGINIA
HDSA Center of Excellence at University of Virginia
Charlottesville, VA
Social Worker: Kenneth Cady, MSW, LSW
Tel: 866-290-4528
Email: KLC2S@virginia.edu

WASHINGTON
HDSA Center of Excellence at University of Washington
Seattle, WA
Social Worker: Donna Ross, MSW, LICSW
Tel: 206-598-8753
Email: donnagr@u.washington.edu

WISCONSIN
Wisconsin Chapter
Wauwatosa, WI
Social Worker: Jean Morack, ACSW, MSW
Tel: 877-330-2699
Email: jmorack@ameritech.net
HDSA Resource Directory

HDSA Centers of Excellence program serves as the cornerstone of HDSA’s commitment to care. These 21 facilities provide a vast array of medical and social services to HD families nationwide and work in collaboration with HDSA chapters, affiliates, regions and support groups to form a seamless national network of resources and referrals for those affected by HD and their families.

HDSA Centers of Excellence also offer family members the opportunity to be a part of the search for effective treatments and a cure through clinical trials. As research advances, there will be a greater need for individuals who want to be a part of finding the answers. To find out more about clinical trials in your area, please visit the Huntington Study Group at www.huntington-study-group.org.

Each HDSA Center of Excellence receives an annual grant of $50,000 from HDSA which is used to support patient and family service programs. These annual grants are funded through special events organized by HDSA chapters, regions, volunteers and friends who recognize the important role that these Centers of Excellence play in providing help to our families. To find out more about fund raising events in your area, please visit the HDSA web site at www.hdsa.org and click on “Community”.

**NEW ENGLAND**
New England HDSA Center of Excellence
Charlestown, MA
Tel: 617-726-5532

**GREATER NEW YORK REGION**
HDSA Center of Excellence at the University of Rochester
Rochester, NY
Tel: 585-273-4147

HDSA Center of Excellence at Columbia Health Sciences/NYS Psychiatric Institute
New York, NY
Tel: 212-305-9172
Website: www.hdny.org

George C. Powell HDSA Center of Excellence at North Shore University Hospital
Great Neck, NY
Tel: 516-570-4477

**MID-ATLANTIC REGION**
HDSA Center of Excellence at Johns Hopkins University/Hospital
Baltimore, MD
Tel: 410-955-2398

HDSA Center of Excellence at University of Virginia Health System
Charlottesville, VA
Tel: 434-924-2665
Helpline: 866-290-4528

**SOUTHEAST REGION**
HDSA Center of Excellence at Emory University
Atlanta, GA
Tel: 404-728-6364

HDSA Center of Excellence at University of Alabama
Birmingham, AL
Tel: 205-996-7865

HDSA Center of Excellence at University of South Florida
Tampa, FL
Tel: 813-974-6022

**GREAT LAKES REGION**
HDSA Center of Excellence at Ohio State University
Columbus, OH
Tel: 614-688-8672

HDSA Center of Excellence at Indiana University School of Medicine
Indianapolis, IN
Tel: 866-488-0008

**SOUTH/SOUTHWEST REGION**
HDSA Center of Excellence at Baylor College of Medicine
Houston, TX
Tel: 713-798-3951

**MIDWEST REGION**
HDSA Center of Excellence
Washington University School of Medicine
St. Louis, MO
Tel: 314-362-3471
Website: www.neuro.wustl.edu/huntington
UPPER MIDWEST REGION
HDSA Center of Excellence at
Hennepin County Medical Center
Minneapolis, MN
Tel: 612-873-2595 (new appointments)
Tel: 612-873-2515 (appointments)
Tel: 612-873-2522 (nurse line for established
patients)
HDSA Center of Excellence at
University of Iowa Hospitals and Clinics
Iowa City, IA
Tel: 319-353-4307
Web site: www.uihealthcare.com/depts/
huntington'sdisease
HDSA Center of Excellence at
Rush University Medical Center
Chicago, IL
Tel: 312-563-2900

ROCKY MOUNTAIN REGION
HDSA Center of Excellence at
Colorado Neurological Institute
Englewood, CO
Tel: 303-768-4600

NORTHWEST REGION
HDSA Center of Excellence at
University of Washington
Seattle, WA
Tel: 206-598-4030

NORTHERN CALIFORNIA REGION
HDSA Center of Excellence at
University of California
Davis Medical Center
Sacramento, CA
Tel: 916-734-6278

SOUTHERN CALIFORNIA REGION
HDSA Center of Excellence at
University of California, Los Angeles
Los Angeles, CA
Tel: 310-794-1225
HDSA Center of Excellence at
University of California, San Diego
San Diego, CA
Tel: 858-622-5824